

Breast Cancer Care-Seeking Behavior in Rural Bangladesh
The Role of Stigma, Gender Identity, and Violence Against Women

by

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ABSTRACT

While women in higher income countries can expect to survive a diagnosis of breast cancer, women in lower- and middle-income countries such as Bangladesh have mortality rates near 50%, suggesting that there are significant barriers to care seeking for breast problems. Given limited literature on barriers to care among native, rural South Asian populations, this study thus sought to understand 1) the impacts of breast problems on women and their families, including the extent of abuse among women with breast problems, and 2) the barriers and facilitators of care for women with breast problems in rural Bangladesh.

Sixty-three study participants (43 women and 20 men) were interviewed about their experiences. Interviewers elicited barriers to care, facilitators of care, and questions about the attitudes and behaviors of family and community members were in structured interviews.

The study found that breast problems and their treatment put significant resource and emotional strains on the family. Furthermore, over a third of women in this study reported abuse of some kind, with emotional abuse, neglect, and abandonment being the most frequently reported.

The study reinforced barriers to care identified in the literature for South Asian populations, but only a quarter of participants reported stigma of any kind. Lack of knowledge about breast cancer and inability to pay for care were the most frequently reported barriers, followed by access to care and fear of treatment. Facilitators of care among women who received a biopsy point to the importance of support by the husband

and husband's family, as well as the ability to identify economic support for and knowledge about care.

This study contributes to the understanding of two overarching themes: structural violence and the value of women, as well as how these themes influence poor outcomes for women with breast cancer in rural Bangladesh. Suggestions for future studies and short and long-term interventions to address study findings are offered.

DEDICATION

I dedicate this dissertation to the people of Bangladesh. It is my hope that this dissertation will, if even in some small way, influence efforts to reduce the suffering of women and their families dealing with breast cancer.

ACKNOWLEDGMENTS

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PREFACE

This inquiry is the result of a desire to understand why women in rural Bangladesh experience significant delays in care and poor health outcomes for serious breast problems. Formative interviews with and anecdotal reports from rural women from the Khulna Division of Bangladesh revealed that some women delayed or never received care out of fear of or actual violence from their husbands and family members. Neglect, abandonment, divorce, and even murder were reported in direct relationship to a possible or diagnosed case of breast cancer. Whether this was a more widespread phenomenon, and why this was occurring were of great interest to this researcher, and important to the development of effective, culturally sensitive breast care programs in Bangladesh. No existing studies could be identified that explored the relationship between breast cancer and abuse in Bangladesh or elsewhere.

This document pursues a number of avenues to gain insights more generally to the circumstances rural women with breast problems and their families encounter. Chapter 1 begins with a presentation of the situation of breast cancer, with a focus on South Asian populations. Chapter 2 then provides an in-depth review of barriers to breast cancer care from both theoretical and applied perspectives, followed by an examination of the influence of Islam on health seeking behavior in Chapter 3, an important consideration given that over 80% of Bangladesh's population is Muslim. Chapter 4 begins a closer exploration of Bangladesh, describing the characteristics of the land, its people, and the situation of breast cancer as we know it today, including known barriers to care. Chapter 5 then examines the theoretical constructs of importance to understanding violence

against women, particularly that experienced by women with breast cancer in Bangladesh. Chapter 6 introduces the study design used to explore the issues of violence, stigma, and gender identity as they relate to a potential diagnosis of breast cancer in the Khulna Division. Chapter 7 provides a close look at the study sample and suggests how it compares to the general population of the Khulna Division. Chapter 8 and Chapter 9 show the results of two distinct study questions: 1) How does a potential diagnosis of breast cancer impact the lives of Bangladeshi families, and 2) What factors influence women's breast care-seeking behaviors? Chapter 10 ties together what we know about breast cancer, theoretical constructs, the context of Bangladesh, and the results of the study to identify challenges to the literature, overarching themes, and potential strategies to reduce delays in care and achieve better outcomes for women in Bangladesh with serious breast problems.

CHAPTER 1

THE PROBLEM OF BREAST CANCER

Breast Cancer as a Growing Global Problem: The Case of Lower- and Middle-Income Countries versus Higher Income Countries

Globally, breast cancer is the leading female cancer and, despite stable or declining incidence in North America and Europe (Torre et al., 2015), is growing in incidence in parts of the world with low- or middle-income countries (LMIC, as described by the World Bank) (The World Bank, n.d.-a), and in areas at the lower end of the United Nation's Human Development Index (HDI)(Bray, Jemal, Grey, Ferlay, & Forman, 2012; Bray, Ren, Masuyer, & Ferlay, 2013). Although breast cancer incidence remains lower in LMIC and lower HDI countries, it is projected that by 2030 there will be approximately 2.4 million new cases of breast cancer annually, with nearly 40% in lower HDI countries (Ferlay et al., 2013). Increasing population size, population ageing, and the transition to a more affluent lifestyle involving delayed reproduction, reduced breast feeding, higher fat diets and obesity, and earlier age at menarche, among other factors, contribute to this growth (Bray et al., 2012; Porter, 2008; Torre et al., 2015). Increased use of hormone replacement therapy has also contributed to the rising incidence in some high-income countries ("Breast cancer and hormone-replacement therapy in the Million Women Study," 2003; Glass, Lacey, Carreon, & Hoover, 2007).

Furthermore, although more women in higher HDI countries are diagnosed with breast cancer overall, women in lower HDI countries are much more likely to die of the

disease: the mortality to incidence ratio for women in higher HDI countries is 2/3 of that of women in lower HDI countries (Bray et al., 2012). Facilities and equipment to treat women with breast cancer are insufficient to treat the existing cases (Ginsburg, 2013; Pal & Mittal, 2004; Story et al., 2012), and many women die without the support of palliative care (El Saghir et al., 2011).

Studies of immigrant populations from LMIC and lower HDI countries have shown that these trends continue after immigration but appear to change over time in both positive and negative ways. These immigrants have overall lower rates of breast cancer (Arnold, Razum, & Coebergh, 2010). Longer time since immigration to a higher HDI country is related to increases in breast cancer incidence (Stotter, Jenkins, Edmondson-Jones, Blackledge, & Kearins, 2014; Velikova, Booth, Johnston, Forman, & Selby, 2004) and decreases in mortality (Kliwer & Smith, 1995). The process of acculturation plays out in these findings as immigrant populations adopt more of the behaviors and attitudes of their host country. While not strictly a linear process, our knowledge about acculturation would suggest that the longer an immigrant has been in the host country (or the further a person is from the first generation immigrant), the more this person adapts to the environment of the host country (Salant & Lauderdale, 2003).

South Asia is home to approximately 40% of the world's population that lives on \$1.25 a day or less ("South Asia Overview," n.d.) and, as would be expected, comprises a number of LMIC and lower HDI countries and their related health concerns. For the purposes of this document, I use the World Bank classification of South Asia, with the exception of the Maldives and Sri Lanka, given their higher HDI levels (ranking at the top of the medium HDI, and high HDI group, respectively). Thus, countries included in

this definition of South Asia consist of Afghanistan, Bangladesh, Bhutan, India, Nepal, and Pakistan. These countries share characteristics, described in more detail in the following pages, which make them distinctive from other LMICs and lower HDI countries such as in parts of Africa. As such, they are a large and important group to study independently.

Breast cancer is the most prevalent type of cancer among women in South Asia, with the exception of India, where cervical cancer is more prevalent (Youlden et al., 2012). As is the case for LMIC and lower HDI countries, South Asia appears to follow the trend of lower overall incidence of breast cancer (Agarwal, Pradeep, Aggarwal, Yip, & Cheung, 2007; Hossain, Ferdous, & Karim-Kos, 2014; Sankaranarayanan et al., 2010), but a greater overall ratio of incidence to mortality (Agarwal et al., 2007). It should be noted, however, that the lack of available cancer and death registries make it difficult to confirm these reports on a larger scale (Hossain et al., 2014; Porter, 2008; Yip & Taib, 2014).

Background: South Asia

While South Asian countries, and often regions within these countries, vary significantly in language, culture, terrain, and other distinctive factors, they share commonalities, including country-level income, human development, gender inequality, and religion, that support the study of this region as a unit. All South Asian countries fall within the World Bank low income (Nepal, Afghanistan; GNI per capita is greater than or equal to \$1,045) or lower middle-income categories (Bangladesh, Bhutan, India, Pakistan; GNI per capita ranges from \$1,046 to \$4,125), which together are described as LMIC. By comparison, the Organization for Economic Cooperation and Development

countries (OECD) have an average GNI per capita of \$38,949, and are primarily classified as high income economies (Table 1) (The World Bank, n.d.-c). Some South Asian countries, such as India, include highly developed cities and greater income inequality, but all South Asian countries share a significant percentage of their population living in impoverished conditions with limited access to modern infrastructure including, among other things, modern health care. The discrepancy in availability of resources is particularly pronounced in the rural-urban divide, where rural inhabitants may not only be limited by the availability of services, but by their ability to access remote services as a result of poor roads, poverty, or other environmental factors.

Using a broader measure of development based on health, education, and income, the United Nations Development Programme (UNDP) defines these countries as medium or low Human Development Index (HDI) countries,” (“Human Development Index (HDI) | Human Development Reports,” n.d.) (Table 1), together referred to as lower HDI countries in this dissertation. The HDI includes the following measures:

- Reproductive health measures: maternal mortality ratio and adolescent birth rates
- Empowerment measures: proportion of parliamentary seats occupied by females and males aged 25 years and older with at least some secondary education
- Economic status measures: labor force participation rate of female and male populations aged 15 years and older.

Furthermore, South Asian populations have a higher degree of gender inequality than OECD countries, as measured by the UNDP scale of gender inequality, the Gender Inequality Index (GII) (Table 1).

These measures each provide a degree of insight to how development affects health, and the fact that health in South Asia is generally poor, relative to other parts of the world. As a result of economic and health improvements, however, LMIC and lower HDI country populations, including those in South Asia, are living longer lives, which is contributing to a transition in their health profile. These countries not only continue to struggle with infectious diseases now eradicated or extremely limited in the Western world (e.g., tuberculosis, malaria), but as a result of longer lives and changing lifestyle habits, they are also facing the growing threat of non-communicable diseases like cancer. This results in an enormous burden on already strained and inadequate health services.

Table 1: Selected Development Indicators

Country/Region	Gross National Income per capita (\$ US, 2011)	Human Development Indicator (2013) ¹	Gender Inequality Indicator (2013) ²
Afghanistan	1,904	0.468	0.705
Bangladesh	2,713	0.558	0.529
Bhutan	6,775	0.584	0.495
India	5,150	0.586	0.563
Nepal	2,194	0.540	0.479
Pakistan	4,652	0.537	0.563
OECD Countries	38,949	0.756 \leq	0.376 \geq
Sub-Saharan Africa	3,152	0.502	0.578

¹Lower numbers indicate less human development

²Higher numbers indicate greater gender inequality

Another common factor of South Asian countries is that they share a large percentage of the world's population of Muslims, and the largest population of Hindus worldwide in India and Nepal. Buddhism is the next most prevalent religion, most frequently practiced in Bhutan, and to a lesser degree in Nepal (Table 2) (CIA, n.d.).

Table 2: Distribution of Religions in South Asia (Percent of the Population)

Country/Region	Muslim	Hindu	Buddhist	Other*
Afghanistan	99.0%	--	--	1.0%
Bangladesh	89.5%	9.6%	--	0.9%
Bhutan	--	22.1%	75.3%	2.6%
India	14.2%	78.8%	--	3.7%
Nepal	4.4%	81.3%	9.0%	5.2%
Pakistan	96.4%	--	--	3.6%

*Any religion represented by less than 4% of the population was placed under “Other”

Finally, alternative medicine in the form of homeopathic doctors, spiritual doctors, “quack” doctors and ayurvedic doctors is widely available and accepted in South Asia, unlike in Western countries. Alternative medicine is often the first line of treatment for individuals in South Asia, and is rooted in a long history of practice.

In sum, other countries and regions of the world may share in some or many of the attributes of South Asian countries, but the unique combination of these macro-level factors warrant the study of South Asian women separately from other parts of the world.

The Epidemiology of Breast Cancer among South Asian Populations

Incidence, Prevalence, and Mortality in South Asia

South Asia also shares commonalities in levels of breast cancer incidence, prevalence, and mortality with other LMIC and lower HDI countries. The dramatically larger incidence to mortality ratios are due, in part, to longer delays between recognition of symptoms and first diagnosis than seen in women in higher income countries. (Anderson, 2010; Coughlin & Ekwueme, 2009; Story et al., 2012). Delay in presentation of breast cancer has been shown to result in breast cancer that is more difficult and more expensive to treat (Jassem et al., 2014), and to result in poorer outcomes (E. C. Smith,

Ziogas, & Anton-Culver, 2013). Understanding exactly why South Asian women delay seeking care is essential for the provision of effective services.

South Asian Immigrant Populations

South Asians represent one of the fastest growing immigrant populations in the UK, US, and Canada, as well as other parts of the world (Patel, Rajpathak, & Karasz, 2011). Studies in the UK have shown that breast cancer incidence and prevalence rates, while lower than the population as a whole (McCormack, Mangtani, Bhakta, McMichael, & dos Santos Silva, 2004; Stotter et al., 2014), are increasing among South Asian populations over time (Stotter et al., 2014; Velikova et al., 2004) and that these populations typically present at a younger age (Leong et al., 2010; Velikova et al., 2004), wait longer to be diagnosed, and have larger primary tumors than the population as a whole (Ginsburg et al., 2015; Velikova et al., 2004). Two studies found that Bangladeshi immigrant women experience lower mortality rates from breast cancer than the population as a whole (Balarajan & Raleigh, 1997; Wild, Fischbacher, Brock, Griffiths, & Bhopal, 2006), and another found mortality to be similar to the population as a whole (Velikova et al., 2004). Immigrant populations have also been found to use breast cancer screening (whether it is self-breast exam, clinical breast exam or mammography) at lower rates than the population in general (Forbes et al., 2011). Furthermore, Gomez, et al. (2010) found that Asian immigrants to the US die of breast cancer more frequently than US born-Asian women do.

While breast cancer in LMIC may not be as prevalent as other communicable diseases or when compared to higher-income countries, its impact on the quantity and quality of South-Asian women's lives is considerable. Breast cancer incidence and

prevalence projections among South Asian women indicate that the problem is only growing, and that mortality is far in excess of that seen in higher-income countries, despite its lower incidence. Trends in higher-income countries, however, suggest that strategies to improve early detection and start treatment at an earlier stage of diagnosis can be highly effective in making breast cancer a disease that most women can survive. Chapter 2 will therefore explore barriers to breast cancer care from theoretical and applied perspectives, with a focus later in the chapter specifically on barriers identified in the literature for South Asian populations.

CHAPTER 2

BARRIERS TO BREAST CANCER CARE

Advances in breast cancer care have greatly reduced the impact of breast cancer in high-income countries in a relatively short period. While some of the reductions in mortality can be attributed to a combination of screening and improved treatment modalities, studies have illustrated that the biggest reductions in breast cancer mortality were the result of increased awareness of the availability of successful treatment, high-quality primary care systems that addressed cultural barriers to access, and an effective referral system for surgical and hormonal treatment (Devi, Tang, & Corbex, 2007; Shulman, Willett, Sievers, & Knaul, 2010). These studies illustrated that expensive equipment or drugs are not needed to diagnose and treat disease at an earlier stage.

The study of barriers to seeking or receiving care has played a prominent role in understanding why people do or do not receive care for breast cancer. This chapter explores barriers to breast care first from various theoretical perspectives, followed by an exploration of macro and individual level barriers identified through a literature review of the topic.

Theoretical Perspectives on Barriers to Breast Cancer Care

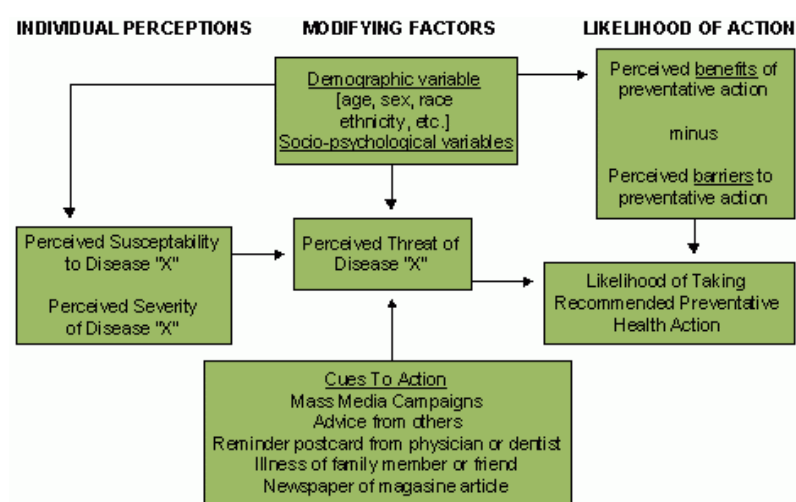
The concept of barriers to care has been incorporated into some well tested and accepted theoretical models of health behavior which emphasize to varying degrees the importance of individual and environmental factors as inhibiting (creating a barrier to) or promoting (facilitating) desired health outcomes. The most commonly used models incorporating the concept of barriers are the Health Belief Model, Social Cognitive

Theory, the Theory of Planned Behavior, the Behavioral Model, and the Socio-ecological Barriers Model described below.

Health Belief Model

The Health Belief Model (HBM) (Rosenstock, 1966), developed in the 1950s to help explain why people did not adopt preventive and screening behaviors for asymptomatic disease (Janz & Becker, 1984), is the most widely accepted model explicitly identifying barriers as a factor in determining whether people take recommended preventative health actions. Since first published, scholars have cited the HBM thousands of times and have used it to explain and predict health behaviors in a broad range of domains, as well as to guide the development of health interventions. A

Figure 1: The Health Belief Model



review of 29 HBM-related studies conducted between 1974 and 1984 found “perceived barriers” to be the most significant factor in determining a variety of health-related behaviors (Janz & Becker, 1984), although none of these studies incorporated barriers into the study of health care seeking specifically for a breast cancer symptom. However, a review of thirteen studies about breast cancer screening using the Health Belief Model conducted in the US between 1984 and 1987 found six models that incorporated the

concept of barriers in predicting the use of mammography, and one for breast self-exam and clinical breast exam. All studies found barriers to be significantly related to uptake of these services (Curry & Emmons, 1994). Lack of physician advice for screening was cited as a major barrier in these studies.

The HBM is a psychosocial model in which an individual's values, perceptions, and beliefs play a significant role in their behaviors. Figure 5 depicts the full model. The model is notable for treating structural features such as access to health services as an indirect influence, placing a more direct emphasis on the individual perceived threat and perceived benefits and barriers to action in influencing health action.

Social Cognitive Theory

The Social Cognitive Theory (originally called Social Learning Theory) presented by psychologist Albert Bandura (A. Bandura, 1986), is a theory of human behavior which posits that both personal and environmental factors contribute to behavior in a reciprocal fashion (Figure 6). Social Cognitive Theory has contributed to the Health Belief Model (as acknowledged by the authors of the Health Belief Model) through the concept of self-efficacy, or one's belief that one can do something to produce a desired outcome.

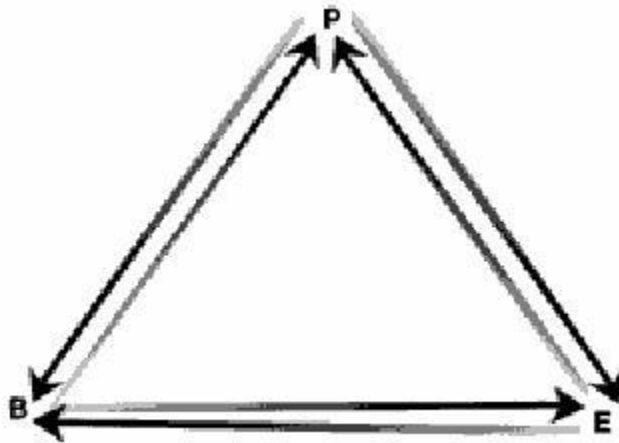
Bandura states that raising self-efficacy for a particular behavior (both mental and physical) will ultimately lead to effective conduct of those behaviors (Bandura, 1998).

Bandura states that barriers "form an integral part of self-efficacy assessment" and "must be measured against gradations of challenges or impediments to successful performance" (Albert Bandura, 1998). Rosenstock, et al. (1988) agrees that the Health Belief Model should incorporate self-efficacy as an explicit component (rather than as a barrier). This distinction, he feels, will make the model more predictive and provide more information

for new research areas and implementation (Rosenstock, Strecher, & Becker, 1988).

Social Cognitive Theory is a much broader theory of human behavior than the HBM and expands our understanding of health behaviors through the emphasis of direct environmental influences on behavior.

Figure 2: Social Cognitive Theory Diagram (P= Personal, B= Behavior, E=Environment)

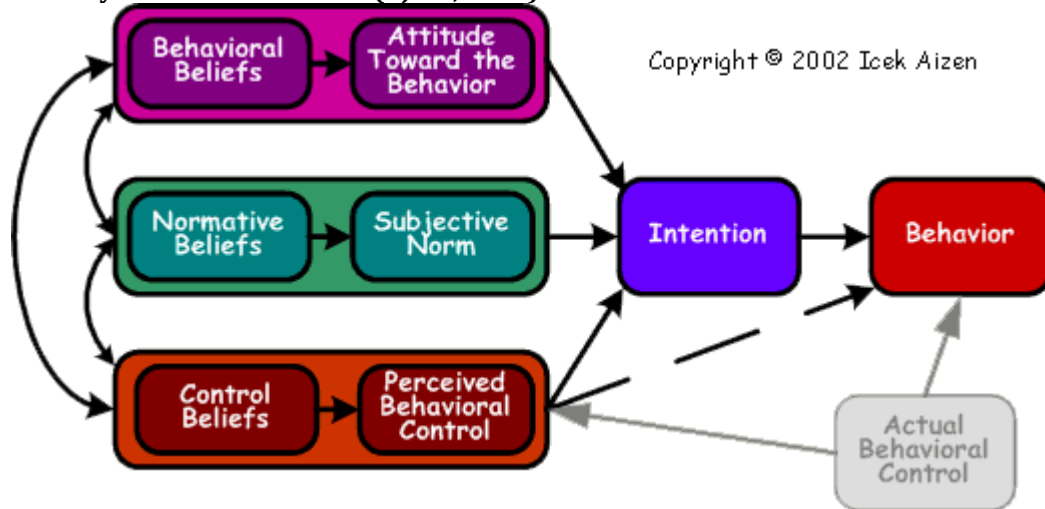


Theory of Planned Behavior

Another model, the Theory of Planned Behavior (Ajzen, 1985) is an extension of an earlier model called the Theory of Reasoned Action (Ajzen, Fishbein, & Heilbroner, 1980). This theory suggests that intentions are the best predictor of behavior, influenced by behavioral beliefs and attitudes, normative beliefs (what others believe) and subjective norms (what an individual thinks other people thinks), and control beliefs and perceived behavioral control. Perceived behavioral control is an extension of the Social Cognitive Theory concept of self-efficacy. Each of these components can act as a barrier to desired health outcomes and thus the contributions of the Theory of Planned Behavior are important to understanding and addressing barriers as a whole. This model, as with the Health Belief Model and Social Cognitive Theory, has also been widely used to explain and predict health behaviors, though its use in explaining barriers to breast screening

uptake is limited to one study reviewed by Curry and Emmons (1999) which found a relationship between barriers and use of mammography.

Figure 3: Theory of Planned Behavior (Ajzen, 1985)



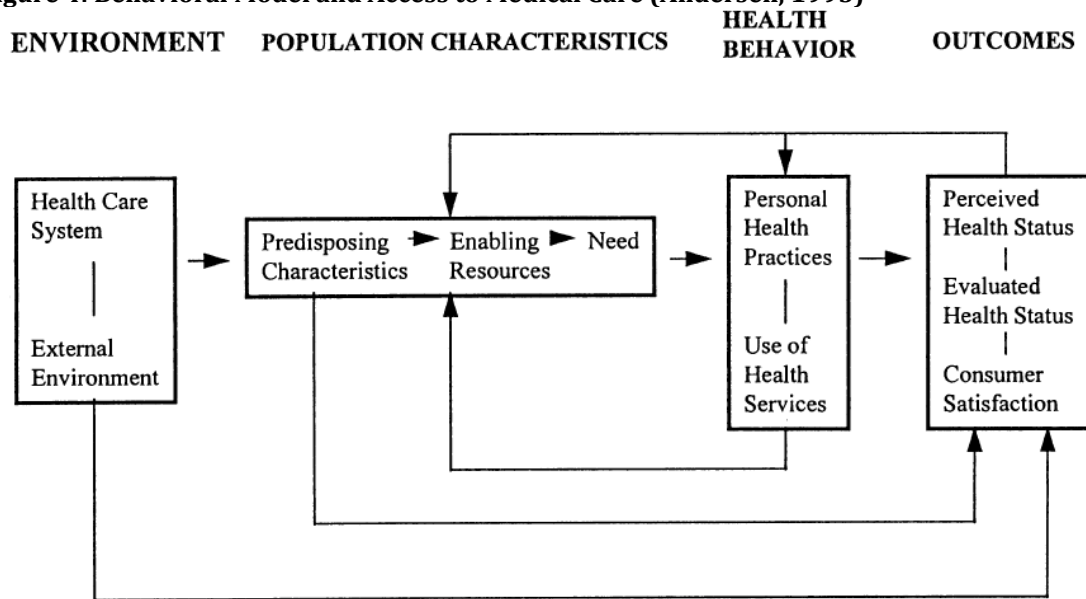
Behavioral Model

Medical sociologist Ronald Andersen proposed the Behavioral Model to explain use of health care services in the 1960s (R. Andersen, 1968) and has modified his model over the years to incorporate explicitly the role of the health care system and external environment, population characteristics such as demographics, enabling resources and actual need for services, and health behaviors as influencing a more broad definition of outcomes (perceived health status, evaluated health status (by medical community), and consumer satisfaction (R. M. Andersen, 1995). The model also recognizes a feedback loop from outcomes back to population characteristics and health behaviors, as well as direct linkages from the environment, population characteristics and behaviors to outcomes. While Andersen does not use the word “barrier” in the model, he addresses the concept of a barrier through his extensive definition of access. He notes that the purpose of the model is to “discover conditions that either facilitate or impede utilization,”

suggesting the model will uncover both aids and barriers to use. Andersen describes access as potential access (via enabling resources), realized access (actual use of health services), equitable access (influenced by demographic characteristics and need), and inequitable access (influenced by social structure, health beliefs and enabling resources). Andersen also introduces the idea of mutability, suggesting that some variables within the model are more changeable than others are, and it is the more mutable areas that are ripe for intervention. Enabling factors and health beliefs are considered more mutable than other variables in the structure. The cyclical nature of this model suggests that removing barriers can have broad effects on the health care system and population as a whole over time.

The most recent version of Andersen's model is in Figure 4, below:

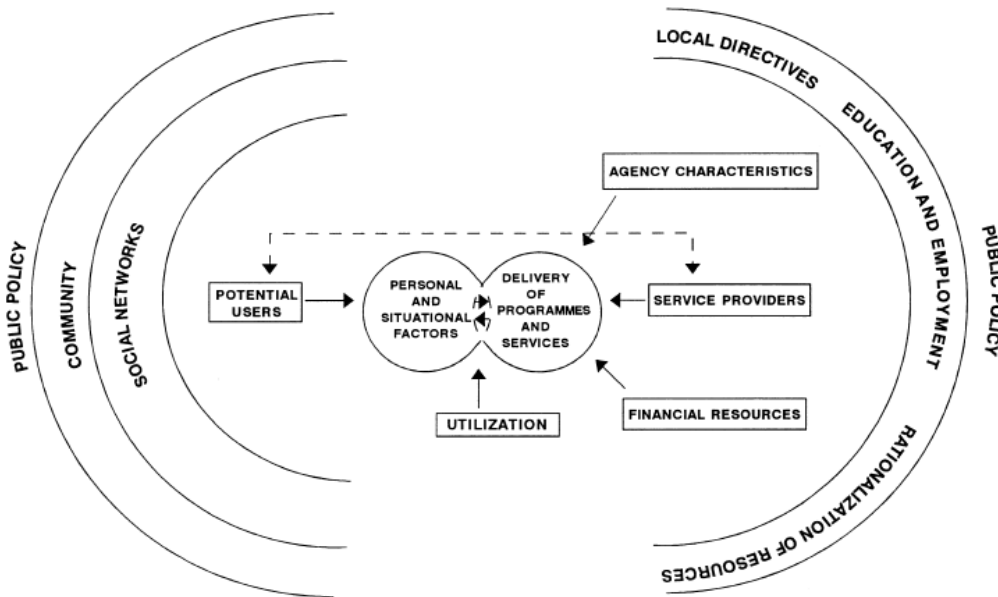
Figure 4: Behavioral Model and Access to Medical Care (Andersen, 1995)



Socio-ecological Barriers Model

Models which attempt to explicitly acknowledge the identification of barriers and their influence on health service use have been proposed by academics in the nursing field, including a model proposed by Wendy Sword (Sword, 1999) to explain barriers to prenatal care. Sword draws on Bandura's Social Cognitive Theory and socio-ecological models, which emphasize the role of the environment as a determinant of health behavior. Sword's model places the potential user of health services and service providers within the wider sphere of public policy, community, and social networks that act on them and influence personal circumstances and how programs are delivered, ultimately affecting the use of services. This model is similar to Andersen's in its attempt to convey the role of external influences on both the individual and the health system/health provider and to provide a lens through which to identify and address barriers at each point. Figure 9, below, depicts Sword's model:

Figure 5: A Socio-Ecological Model of Determinants of Health Services Utilization (Sword, 1999)



Each of these models emerged from different disciplines and emphasized unique areas as important to understanding the predictors or barriers to taking action for a health problem. While the tendency may be to pick and choose variables from each model to create a model uniquely suited to a particular health scenario, Bandura (Albert Bandura, 1998) cautions against this as many seemingly different variables between models actually measure very similar things under different names. The potential for redundancy and weakening of models through a combination of variables is high in these circumstances.

Limitations of Theoretical Models and Future Needs

Each of these models has been applied to numerous health behaviors and outcomes. These models have individually been shown to have explanatory value in many instances; however, it is important to note that many studies have focused on White populations from higher income countries. Additionally, the enormous variability in how model concepts are defined by individual researchers makes it difficult to determine the relative value of models for identifying health measures (barriers, in particular) and outcomes of interest (Melnik, 1988). A review of the predictive value of each of these models (and the role of model components such as barriers) relative to each other is needed for health concerns such as breast cancer (and for specific aspects of breast cancer such as early detection), a view shared by Curry and Emmons (1999). Furthermore, a review of how well models are able to account for the variation in barriers that occur across different cultural contexts is also needed. These reviews would allow interventionists to select the model best suited to predicting or explaining the behavior of

interest and facilitate more targeted research leading to expansion or modification of models with potentially greater predictive value, or perhaps new models.

Furthermore, as suggested by researchers such as Sword (1994), theory grounded in barriers is in need of further development. Remennick (2006) suggested that interventions that can address barriers to breast cancer care in a culturally sensitive manner are more effective in their aims. Developing the concept of barriers more fully is an important task “because it provides a theoretical link between the study of health-related behavior and health services research: a view of the health care delivery system through the eyes of the consumer and a new vehicle for examining the dynamic between the consumer and the health care system” (Melnik, 1990, p. 108), and as noted by Remennick (1999) may have important implications for health outcomes.

Curry and Emmons (1999) caution that it is important to recognize that theories that help explain the use of breast screening services (or any health behavior for that matter) are not necessarily useful for designing interventions for the same purpose. A variety of theories may be needed to address the vast social, psychological, and environmental factors, which comprise barriers to care for a given health, issue.

An additional concern noted by Bandura (1998) is that “...most of the models of health behavior are concerned mainly with predicting health habits, but they offer little guidance on how to change them” (630). Indeed, while some behavioral models may suggest modes of addressing barriers, a comprehensive effort to address barriers and ultimately change behavior involves a multi-disciplinary approach.

Barriers Identified in South Asia in Published Studies: Macro and Individual Level

Barriers

As noted previously, one of the major limitations of current theoretical models of health behavior is the insufficient development and testing of models among non-White, underserved populations around the world. Furthermore, the limited model testing that has been conducted has suggested that current health theory constructs are not helpful for understanding health behavior in cultures where decisions are made as a family unit as opposed to through individual volition (relational or familial cultures vs. individualistic cultures) (Pasick et al., 2009). This finding suggests that explanatory models for breast cancer screening, diagnosis, and treatment need to start with a qualitative exploration of the influences on care seeking in relational cultures. A review of known barriers to breast cancer care amongst South Asian populations is a launching point from which more theoretically meaningful models may be developed.

To begin the exploration of barriers to breast care faced by women in South Asia, I conducted a literature review of published studies and reports between 2000 and 2015, including prior literature reviews of the same topic, expert panels, and individual studies. Studies examining barriers to screening, diagnosis, and treatment of breast cancer were included. I provide additional details about how I designed and conducted this literature review in Appendix A.

Prior Reviews of Barriers to Breast Cancer Care among South Asian Populations
Previous reviews of published studies addressing barriers to breast cancer care among South Asian populations have focused on screening behaviors of immigrants (Bedi & Devins, 2015; Crawford, Ahmad, Beaton, & Bierman, 2015), “cultural

considerations” for a mixture of immigrant and native South Asian women (Bedi & Devins, 2015), interventions to increase breast cancer screening uptake among immigrant and native Asian (including South Asian) women (Remennick, 2006), and barriers in developing countries, including South Asia, resulting in delayed patient care seeking (Sharma, Costas, Shulman, & Meara, 2012).

Crawford et al. (2015) identified a number of themes in the literature related to South Asian immigrants’ cancer screening behaviors in the US, Canada, and UK—breast cancer screening being one of a number of cancer screening behaviors examined. Important influences on whether screening was conducted or not included the role of family, having a holistic view of healthcare (i.e., mind and body connection), fatalism (e.g., “breast cancer is a death sentence”), the belief that screening is not needed, fear, and other emotional perceptions about screening, lack of knowledge about cancer and/or screening, lack of access to screening due to personal factors or structural factors, stigma, and the role of gender in screening uptake. The authors note that there is heterogeneity in the South Asian culture that must be considered, and that further research is required to understand gender-specific factors that influence screening.

Bedi and Devins (2015) examined the psychosocial impact of breast cancer in South Asian immigrant women in 23 studies. Themes identified included stigma (resulting in isolation, compromised family standing, and reduced marriage prospects for the patient and female family members), low priority of women’s health (i.e., women did not want to neglect their family responsibilities or worry family members), modesty and stoicism (affecting their willingness to discuss and be examined for disease), lack of awareness, and beliefs (i.e., believing it is caused through curses, or believing it is fatal).

The authors conclude that culturally sensitive care should address these themes in practice. Both Crawford, et al. (2015) and Bedi and Devins (2015) identified similar themes and conclusions.

Sharma, et al.'s (2012) review of barriers resulting in delayed patient care for women in developing countries included 13 articles, and concluded that the strongest support was for lower education and lower income, along with being unmarried, divorced or widowed as influences on delays in care (although being widowed was found to have mixed results). They found less evidence for the influence of sociocultural variables but concluded that there is a lack of high-quality research on those variables.

In a review of immigrant and minority women's (including Muslim women's) use of early breast cancer detection services, four categories of barriers were identified, including structural, organizational, psychological and sociocultural (Remennick, 2006). Table 3 lists barriers within these categories.

Table 3: Barriers to Breast Cancer Screening Among Immigrant and Minority Women in Multicultural Societies (reproduced from Remennick, 2006)

<p>Structural Barriers</p> <ul style="list-style-type: none"> • Lack of or limited health insurance • Long distance to a screening facility • Lack of transportation • Inability to take time off from work • Inability to pay for child care <p>Organizational Barriers</p> <ul style="list-style-type: none"> • Difficulty understanding and navigating the health care system • Language barriers between women and providers • Arrogance or brusqueness of medical staff • Lack of female providers <p>Psychological barriers</p> <ul style="list-style-type: none"> • Fear of cancer • Denial of susceptibility • Fatalism, often stemming from religious beliefs • Fear of and lack of knowledge about cancer treatment • Belief that treatment is futile <p>Sociocultural barriers</p> <ul style="list-style-type: none"> • Complete dependence of women on men in some cultures • Subservient status of women in the family and the household • Possibility of being abandoned after a diagnosis of breast cancer
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Remennick notes that Muslim women in particular face barriers due to Islamic prohibition of female nudity in front of a man other than her husband (the fear of shame being worse than death), the view that survival or death is a matter of providence, and that women are dependent on men for income, a sense of identity and self-esteem. These barriers frequently lead to delays in seeking care (if care is at all sought), resulting in

more advanced stage and less curable cancers as illustrated in earlier sections of this paper.

Expert Opinion on Barriers to Breast Cancer Care among South Asian Populations

Among medical professionals and researchers working with South Asian breast cancer patients, there is a general call to understand the unique circumstances of these women, and particularly the barriers they face in obtaining screening, breast cancer diagnosis, and treatment (Agarwal et al., 2009; Anderson, 2010; Ginsburg, 2013). These scholars believe that barriers to care cause delays in addressing disease, which results in more advanced disease at diagnosis, more invasive treatment modalities, and greater mortality.

The Global Summit Consensus Conference on International Breast Health Care in 2002 was a major effort to bring together representatives from many low- and middle-income countries (LMIC) countries to discuss breast cancer care. Panels of breast cancer experts from 17 countries and 9 world regions created guidelines to address early detection, diagnosis, and treatment of breast cancer. Barriers identified in providing early detection and treatment of breast cancer are listed in Table 4 (Smith et al., 2006).

Table 4: Barriers to Awareness, Seeking, and Obtaining Care, and Responsiveness to Screening Identified During the 2002 Global Summit

<ul style="list-style-type: none">• Fatalism• Inability to act without husband's permission• Fear of casting stigma on one's daughters• Fear of being ostracized• Fear of contagion• Reticence• Language barriers (including the absence of a word for cancer in some languages)• Preference for traditional healers

These barriers highlight many of the more powerful psychosocial issues surrounding breast cancer in different parts of the world and the fact that Western medicine is not always the first choice of care even for serious disease.

There exists, also, a body of scholars examining what has been termed “structural violence” (Galtung, 1969) to explore why populations experience disadvantage (in the form of low education, poor health, poor quality of life and limited economic opportunities, among other things) as a result of their gender, class, country of origin or other discriminating factors (Farmer, 1996; Farmer et al., 2010). These scholars encourage us to look beyond the direct relationships between variables to pervasive factors in the environment affecting broad populations, such as racism, sexism, or classism. Similarly, the theory of Fundamental Causes (Phelan, Link, & Tehranifar, 2010) illustrates that socio-economic status (knowledge, money, power, prestige, and social connections) influences multiple risk and protective factors for health that affect health outcomes. Habib (2008) argues that in Canada the focus on “culturally sensitive” care has moved attention away from racism and other systemic barriers (or fundamental causes), attributing inequitable access to the culture of women instead. As a result, providers and policymakers have failed to address important contributions to poor health and treatment options created by discriminatory structural issues.

Published Studies on Barriers to Breast Cancer Care (Screening, Diagnosis, and Treatment) in South Asia

I grouped studies identified as part of this literature review by macro- and individual-level themes. Macro-level themes were derived from barriers (factors) that align with characteristics of broad South Asian populations and countries described in Chapter 1. The factors contributing to macro-level themes hierarchically influence

individual-level themes and their related factors. Macro-level themes are barriers that are wholly or in part outside the locus of the individual or family to control barring large-scale societal change or ability and willingness of an individual to go against societal norms. Individual-level themes, however, are suggested by barriers that are more likely to be within the control of the individual (including both patient and healthcare provider) to overcome, and may be more readily addressed through targeted breast health intervention programs. Individual-level themes frequently have a relationship with one or more macro-level themes, illustrating the interconnectedness of findings. Due to the limited number of studies addressing diagnosis and treatment and the large degree of overlap of barriers identified across behaviors, themes are grouped by barriers rather than by screening, diagnosis, or treatment.

Macro-Level Barriers

Poverty/Economic Barriers

Economic barriers such as income level or costs of care were found for breast cancer detection (screening), diagnosis, and treatment and for both immigrant and non-immigrant populations, and were an important factor in delay of care and continuation of treatment for Nepalese (Braun & Itano, 2001) and Bangladeshi women (Haque et al., 2015; Story et al., 2012).

Alternative medicine, used throughout South Asia, was noted by a number of studies of both immigrant and native women as the treatment of first choice primarily for economic reasons, and as a reason for delayed care seeking (Ahmad, Mahmood, Pietkiewicz, McDonald, & Ginsburg, 2011; Bhatt et al., 2011; Haque et al., 2015; Jafri, 2011; Story et al., 2012; Zahid Ali Memon, 2013). Use of alternative medicine was

specifically correlated with longer delays in care versus women who waited for less time to seek care (Zahid Ali Memon, 2013).

Costs were also cited among immigrant populations in countries such as Canada where healthcare is provided free of cost (Lobb, Pinto, & Lofters, 2013a; Meana, Bunston, George, Wells, & Rosser, 2001). Expenses such as transport, time off work and childcare contribute to the barrier of cost, particularly among low-income populations. Indian women in the US also mentioned the role of costs in not going for recommended screening (Sadler et al., 2001).

One large multi-country study examined factors related to breast cancer screening among low-income countries, including South Asia (Akinyemiju, 2012). Household socioeconomic status was found to be a significant determinant of obtaining breast cancer screening. A relationship was also found between lower income and breast self-exam among Pakistani women (Gilani et al., 2010). However, even higher-income women in Bangladesh mentioned cost as a barrier to screening, citing a willingness to pay only a fraction of the actual costs for mammography (Rasu, Rianon, Shahidullah, Faisel, & Selwyn, 2011).

Five studies that specifically examined cost or other economic barriers to care in relation to screening, however, did not find a relationship (see Appendix D for an overview of all studies included in this review).

Education

Lower education level was found to be related to lower levels of BSE ($p < 0.01$) and mammography ($p = 0.03$) among women in Bangladesh (Rasu et al., 2011). However, three additional studies examining education level and screening of South Asian

immigrants in Canada and the US (Farah Ahmad & Stewart, 2004; Hasnain, Menon, Ferrans, & Szalacha, 2014; Islam, Kwon, Senie, & Kathuria, 2006) and one study of women in Pakistan (Gilani et al., 2010) found no relationship.

Access to Care

A survey of over 10,000 women from 15 low-income countries including two in South Asia (Nepal and Bangladesh) found that country health expenditures and availability of mammography services were significantly related to receipt of mammography (Akinyemiju, 2012). Furthermore, this same study and one additional study of screening among Pakistani women (Gilani et al., 2010) found that women in rural areas were less likely to access screening, suggesting an even greater reduction of available screening in rural areas, and potentially other factors that create barriers in rural areas of low-income countries (e.g., poor roads, fewer economic resources, etc.).

The availability of services for diagnosis and treatment was cited as a barrier to care among Bangladeshi women in two studies (Haque et al., 2015; Story et al., 2012). Ability to access available services due to issues such as poor roads, lack of transport, doctors not showing up for scheduled hours or being too overwhelmed with patients to provide needed advice, and being too far away from services were other access issues cited by studies covering screening, diagnosis, and treatment (Ahmad et al., 2011; Haque et al., 2015; Shirazi, Bloom, Shirazi, & Popal, 2013; Story et al., 2012).

Lack of Health Insurance and Health Provider Access

Access, particularly for immigrant populations in countries without national health care, may be dependent on having health insurance, which also affects the ability to see a primary care provider. A relationship between having insurance and screening

(Glenn, Chawla, Surani, & Bastani, 2009; Islam et al., 2006; Wu, Scheffer, & Lee, 2012) among immigrant populations, as well as diagnosis and treatment (Braun & Itano, 2001), and between having a primary care provider and screening among immigrants (Hasnain et al., 2014), was identified in the literature. Two studies examining health insurance and screening (Hasnain et al., 2014), and having a primary care provider and screening (Islam et al., 2006), however, found no relationship.

Role and Value of Women in Society

Women from various South Asian countries noted factors that spoke to their role in society and the value they and other members of their family place on women's health as a priority. While not consistently defined in the included studies, a number of different emerging themes suggested the importance of the role of women. For example, women in Bangladesh mentioned not wanting to take time or money for their own health problems because it would take resources from other family members, particularly children and the ability to educate and provide for them (Haque et al., 2015; Story et al., 2012). Indian immigrants in the US similarly said they did not want to be a burden to their families (Howard, 2004). Both immigrant and native women noted other family responsibilities such as child care, cooking, and taking care of other family members as reasons why they could not go for screening, diagnosis, or treatment (Farah Ahmad et al., 2011; Braun & Itano, 2001; Haque et al., 2015; Meana et al., 2001; Story et al., 2012). Women and men in Bangladesh noted that costs "add up" when considering women's health problems, and that divorce or abandonment is an option in these cases (Story et al., 2012). Lack of support from family members for screening or diagnosis and treatment was also cited as a

barrier for Indian, Pakistani and Afghani immigrant women (Lobb et al., 2013a; Shirazi et al., 2013).

Another statement identified repeatedly in the literature regarding screening that may relate to women's value of their own health is that of "it is not a priority" (Ahmad & Stewart, 2004; Hasnain et al., 2014; Maqsood et al., 2009; Pons-Vigués, Puigpinós-Riera, Serral, et al., 2012; Rasu et al., 2011; Thomas, Saleem, & Abraham, 2005). Both immigrant and native populations used this statement. The role and value of women in society (felt by society, family members, and the woman herself), therefore, becomes an overarching theme that may help explain some of the barriers to breast cancer care that women in South Asia face.

Stigma

Stigma is the devalued identity of an individual because of a particular trait—in this case, breast cancer. According to sociologist Erving Goffman, stigma is a "discrepancy between virtual and actual social identity" (Goffman, 2009). Stigma toward cancer can be a barrier to care and result in isolation of the patient and negative emotions such as shame, self-blame, and guilt (Else-Quest & Jackson, 2014). Different types of stigma have been identified in the literature, including felt (feared by an individual), courtesy (stigma experienced by those associated with a stigmatized person), and enacted (various ways that stigma is enacted on a person being stigmatized) stigma (Jacoby, 1994). Studies described below, found that stigma had a negative influence on care seeking for breast problems.

Bangladeshi women described stigma through such statements as breast cancer is a "curse upon the family", "a curse from God for wrong doings," or "evil" (Story et al.,

2012). Pakistani and other South Asian immigrants mentioned hiding breast cancer patients from other family members and the community, worry about marriage prospects as a result of the disease in their family, or a breakdown of the marriage (Banning & Hafeez, 2009; Karbani et al., 2011). Women in Pakistan described breast cancer as “socially unacceptable” (Banning & Hafeez, 2010). Indian immigrants expressed fear of stigma for such “an ugly disease” (Howard, 2004), and a mix of Pakistani and Indian immigrants in Spain and the US described breast cancer as “taboo” (Pons-Vigués, Puigpinós-Riera, Serral, et al., 2012; Wu et al., 2012). Bangladeshi women reported divorce or abandonment and fear of poor treatment by family members as a result of a breast cancer diagnosis (Haque et al., 2015; Story et al., 2012), suggesting a relationship between stigma and negative outcomes (health and otherwise) for women.

Stigma is described by Authors Yang, et.al (2007) as “a highly pragmatic, even tactical response to perceived threats, real dangers, and fear of the unknown.” Stigma, in their view, stems from things that fundamentally threaten what matters most to people. It may serve a protective role for those who stigmatize but is often dangerous for the stigmatized, reducing their access to needed resources and predisposing them to negative outcomes such as increased stress or adverse mental and physical health outcomes. Cancer itself has been the focus of some studies of stigma. Cancer-related stigma is found more frequently for cancers that are believed to be controllable and is attributed more frequently to people who are believed to “deserve it” (Else-Quest & Jackson, 2014). The descriptions of stigma provided by studies, above, support this assertion.

Religion

As home to some of the largest populations of Hindu and Islamic populations in the world, religion has the potential to play a significant role in how women in South Asia deal with breast cancer. A study of Nepalese women in Nepal found a significant relationship between religion and screening, but a closer examination of the results reveals very small numbers of women outside of the Hindu religion (3 Buddhist, 1 Muslim, and 1 Christian) (Bhatt et al., 2011). Women in a study of South Asian immigrants in the UK noted that they felt it was insensitive to ask women to go for screening during Ramadan when women more frequently remain at home under the Islamic tenet of “purdah.” Furthermore, women felt that only their husbands should see them naked, which could interfere with receiving screening, diagnosis, and treatment. However, these same women said that the Qur’an (the Islamic holy text) could be helpful in promoting health-seeking behavior (Thomas et al., 2005). One study specifically quoted Afghani immigrants as saying that they did not feel Islam was a barrier to breast cancer screening, and that “culture” was responsible, in particular, for women’s modesty (Shirazi et al., 2013). Chapter 4 provides a more in-depth look at the role of Islam in influencing women’s health decisions.

Individual-Level Barriers

Age

Age was identified by three studies as having a significant relationship with screening and diagnosis (Ahmad & Stewart, 2004; Gilani et al., 2010; Glenn et al., 2009). Among South Asian immigrants in Canada, younger age was associated with decreased likelihood of CBE (Ahmad & Stewart, 2004), however among South Asian women in the

US, younger age (approximately 40 years) was associated with an increased likelihood of mammography versus women aged 65 or over (Glenn et al., 2009). Three additional studies did not identify a relationship between age and screening (Hasnain et al., 2014; Islam et al., 2006; Rasu et al., 2011).

Knowledge

Knowledge of breast cancer in general, breast cancer screening, and breast cancer diagnosis and treatment services was the most frequently studied and identified factor as a barrier to breast health care among South Asian women, identified in 17 studies, and nearly equally identified between immigrant and native populations. Five studies, however, did not find a relationship between knowledge and screening (Banning & Hafeez, 2010; Gilani et al., 2010; Hasnain et al., 2014; Meana et al., 2001; Pons-Vigués, Puigpinós-Riera, Serral, et al., 2012; Thomas et al., 2005).

Cross-sectional studies of knowledge and screening, diagnosis, or treatment are limited in their ability to determine whether knowledge was the result of participating in the screening or a reason women went for screening, but qualitative studies have helped reveal that South Asian women feel their lack of knowledge is important. Among immigrant populations, Canadian South Asian immigrants said that they didn't know where to go or who to ask about CBE, and that they didn't know about CBE in general (Ahmad & Stewart, 2004). Pakistani women in the US and the UK also mentioned knowledge of risk factors and screening as a barrier to breast cancer screening (Banning & Hafeez, 2010; Jafri, 2011). A study of Pakistani, Bangladeshi and Indian immigrants in the UK found that lack of knowledge was an important barrier to screening, diagnosis, and treatment (Karbani et al., 2011). Afghani immigrants in the US reported knowledge

as a barrier to screening (Shirazi et al., 2013), and lack of awareness was reported as a barrier among South Asian immigrants in Spain (Pons-Vigués, Puigpinós-Riera, Rodríguez, et al., 2012). Over half (55%) of Indian women in the US felt their knowledge of breast cancer screening was inadequate (Sadler et al., 2001).

Concept mapping of South Asian immigrants in Canada revealed that women felt not only their own knowledge interfered with their ability to receive mammography, but that physician knowledge and health education materials were lacking (Ahmad et al., 2011; Lobb, Pinto, & Lofters, 2013b). A two-center study of educated Pakistani women in the UK and Pakistan found that immigrant women were less informed about BSE than women living in Pakistan and that women in Pakistan were generally more motivated to seek out information (Banning & Hafeez, 2010).

Among native populations, rural Bangladeshi women mentioned the lack of awareness about breast health services in general (encompassing screening, diagnosis, and treatment) as a barrier (Haque, Kawsar, Adibuzzaman, & Uddin, 2014; Story et al., 2012).

Family History

Family history was examined by four studies: two of which found a relationship with screening (Bhatt et al., 2011; Rasu et al., 2011), one with diagnosis (Zahid Ali Memon, 2013), and one found no relationship (Gilani et al., 2010). Among the two studies finding a relationship with screening or diagnosis, women with no family history of breast cancer were less likely to go for screening and more likely to wait longer to go to the doctor with symptoms of breast cancer.

Modesty

Modesty was also frequently cited by South Asian women as a reason for not doing breast cancer screening, diagnosis, or treatment. Modesty was described by women as not wanting to reveal their breasts for exam, discomfort showing their breasts to a male doctor or preference for a female doctor, and shame (Banning & Hafeez, 2010; Bhatt et al., 2011; Haque et al., 2014; Jafri, 2011; Meana et al., 2001; Pons-Vigués, Puigpinós-Riera, Serral, et al., 2012; Shirazi et al., 2013; Story et al., 2012; Thomas et al., 2005). Women also expressed feeling uncomfortable touching their own breasts (Parajuli & Mandal, 2011). In a two-center study of Pakistani women in the UK and Pakistan, immigrant women were more open about their breasts and expressed less modesty (Banning & Hafeez, 2010). Immigrants in other studies, however, still cited embarrassment as a factor (Jafri, 2011; Meana et al., 2001; Pons-Vigués, Puigpinós-Riera, Serral, et al., 2012; Shirazi et al., 2013; Thomas et al., 2005).

Communication with Health Providers

Studies of immigrant women more frequently, but not exclusively, identified communication with health providers as a barrier to breast health care. Immigrant women mentioned difficulty understanding their doctor due to language difficulties (Ahmad et al., 2011; Sadler et al., 2001; Shirazi et al., 2013) or cultural differences (Lobb et al., 2013a; Shirazi et al., 2013). Another study of South Asian immigrants in the UK found that women used confusing or vague language to describe their breasts (e.g., “chest” for “breast”), which could result in miscommunication (Karbani et al., 2011). South Asian immigrants in Canada also provided input about the limited time during exams to discuss cancer screening with their doctor (Lobb et al., 2013a), and other studies found that

doctors were not communicating the importance of breast cancer screening to their patients when they had the opportunity (Jafri, 2011).

A case study of a Nepalese woman undergoing treatment for breast cancer revealed difficulties in communication that were based on educational and status/power differences (Braun & Itano, 2001; Story et al., 2012). This study observed that the doctor did not ask the patient if she had questions or give her a chance to do so, and the patient reported that she didn't feel it would be polite to ask questions about the doctor's practices (Braun & Itano, 2001).

In sum, studies identified many forms of communication as a barrier—among them, language, health system constraints, poor communication of important messages, and status differentials.

Fatalism

Fatalism is a theme that encompasses statements from women such as “there is no cure for cancer,” “there is nothing I can do,” or “it is all in God's hands.” Fatalism was expressed in relation to all forms of breast health care, and among both native and immigrant populations (Banning & Hafeez, 2010; Braun & Itano, 2001; Howard, 2004; Islam et al., 2006; Pons-Vigués, Puigpinós-Riera, Rodríguez, et al., 2012; Story et al., 2012). Fatalism led to such behaviors as hiding the disease from family members so as not to worry them or become a burden (Banning & Hafeez, 2009).

Fear

The theme of fear arose through repeated statements found in the literature by South Asian women that they were afraid of some aspect of breast health care. Women reported fear of pain from the process of receiving screening (Ahmad & Stewart, 2004;

Meana et al., 2001; Sadler et al., 2001; Wu et al., 2012), fear of harmful radiation exposure (Wu et al., 2012), fear of finding out they may have breast cancer as a result of screening (Ahmad et al., 2011, 2011; Lobb et al., 2013a; Meana et al., 2001; Parajuli & Mandal, 2011; Rasu et al., 2011), and fear of treatment and death (Pons-Vigués, Puigpinós-Riera, Serral, et al., 2012; Wu et al., 2012).

Immigrant-specific: Time in Country and Acculturation

Studies of South Asian immigrants found a relationship between the length of time since immigration or the level of acculturation and screening. In general, the longer time since immigration, and the more acculturated, the more likely a woman was to have preventive breast screening (Ahmad & Stewart, 2004; Glenn et al., 2009; Hasnain et al., 2014; Jafri, 2011; Meana et al., 2001; Pons-Vigués, Puigpinós-Riera, Rodríguez, et al., 2012). Women in the Pons-Vigués (2012) study noted that, over time, immigrants take on more of a preventative mindset after living longer in Spain, resulting in increased use of screening such as mammography.

Discussion

Table 5 provides an overview of barriers identified in the literature. The results of this published article review have many similarities to prior reviews of barriers to breast cancer care among South Asian women, supporting earlier findings that psychosocial and emotional issues play as big a role in practicing screening behaviors and receiving diagnosis and treatment as broader structural issues such as poverty and availability of services. In particular, this review responds to Sharma, et al.'s (2012) call for a closer examination of socio-cultural barriers to breast cancer diagnosis and treatment among

South Asian women, and adds to Bedi and Davis' (2015) review of cultural factors related to breast screening.

Barriers identified lend themselves to some conclusions that may provide insight into program development. First, while a number of studies found a positive relationship between knowledge, education, and screening behaviors, there were a number of articles that found no relationship. These mixed results suggest the need for further exploration and a better understanding of how knowledge about breast care is transmitted.

Religion was another theme that had mixed findings for breast cancer screening, diagnosis, and treatment. Whereas some studies drew the conclusion between modesty and religion, illustrating that Islam, in particular, encouraged modesty and forbade their interaction with, other studies concluded that "culture" was a stronger influence on modesty and that religion was actually an empowering and supportive part of their experience of breast cancer, or encouraged preventive health behaviors such as screening. These findings suggest that religion may act as both a barrier and a facilitator of care, depending on its interpretation and that religion is not the only, and perhaps not the primary, cause of modesty among women.

Table 5: Overview of Barriers to Breast Cancer Care among South Asian Populations Identified in the Literature (2000-2015)

<p>Macro-Level Themes</p> <ul style="list-style-type: none"> • Poverty/Economic Barriers • Education • Access to Care, including lack of health insurance or health provider • Role and Value of Women in Society • Stigma • Religion • Use of Alternative Medicine
<p>Individual-Level Themes</p> <ul style="list-style-type: none"> • Age • Knowledge • Family History • Modesty • Communication with Health Providers • Fatalism • Fear • Family History

Only a few studies considered age and these studies had mixed findings. The limited findings, however, suggest that the age of a target audience for intervention, length of time as an immigrant, and the behavior of interest are important considerations. Older immigrant South Asian women who have been in their new country for a shorter period may have more traditional views of modesty, less education, and less knowledge than younger women may have. Health providers may also play a role in findings where screening guidelines target specific age groups. Thus, each of these factors must be considered when interpreting how age may affect breast health behaviors.

Some additional immigrant issues arose that deserve note. Although immigrant populations studied were heterogeneous in nationality, age group, professions, and country of immigration, it is clear that immigrant populations continue to face many of the same barriers that women in their home countries face, such as access, psychosocial

and economic barriers. The two-center study by Banning and Hafeez (2010) suggests that immigrants may sometimes be more isolated and less able to navigate their environment for needed services than native populations, having less access to services in their own language that also cater to cultural differences.

Immigrant studies by Braun and Itano (2001) and Ahmad, et al. (2001) demonstrate that even when health care is provided free of cost, the majority of barriers cited by native women and women in countries without universal coverage of health care remain the same. Just the provision of services is not enough to overcome strong socio-cultural barriers, and cost still remains an issue for many women. This same conclusion was made by Meana, et al. (2001, p. 186) of Sri-Lankan immigrants who stated, "it is difficult to ignore the consistent finding that women of all ethnic groups, educational levels, and economic status will avoid mammograms even when access is as facilitated as it can possibly be. Psychological barriers are clearly central to under-utilization."

There are a few broader observations arising from this review that should also be noted related to the division of themes into macro and micro, interrelationships of barriers, and the role of qualitative studies.

First, the division of barriers into macro and micro themes provides a guide for the types of activities required to make changes in breast health care behaviors. At the broadest level are barriers attributable to many of the "-isms" related to structural violence: racism, classism, sexism, and beyond. These deeply rooted injustices impact not just women with breast cancer, but are revealed in the low priority that women place on their own health, the lack of questioning by women when interacting with higher-class doctors, and the degree of fatalism they express because of their circumstances. The

limited number of studies covering the issue of barriers to breast cancer care more frequently focus on immigrants, who are arguably privileged women by nature of their ability to travel internationally, or incorporate native women who are students or professionals, rather than more typical native populations. Furthermore, many of the in-country studies include urban, more educated populations. As a result, very few of the included studies can speak to the barriers faced by the most vulnerable of South Asian women, those who live in a village and struggle to get by each day. Without more studies of native, underserved populations, it is difficult to make conclusions about how programs can meet the needs of the majority of women who need care.

Macro-level barriers rooted outside of the healthcare system, such as widespread poverty or low education levels among women, are not typically within the scope of a local non-governmental organization (NGO) to change, but this same NGO may choose to find other ways to address the problem. For example, they may obtain subsidies for low-income patients, and address socio-cultural issues such as modesty and fatalism in unique ways. International organizations may assist countries in prioritizing breast cancer detection by illustrating global trends and findings, but may leave the “how” up to individual countries to determine. Widespread poverty, the role and value of women in society, and power differentials will take efforts on all levels, and much longer to change than more malleable factors such as knowledge and awareness of breast cancer screening or services. Thus, it will be important for efforts to be made at many levels over and for extended periods.

Second, it is clear that macro level barriers strongly contribute to one or more individual-level barriers and that interventionists should acknowledge and strategically

use these relationships to influence multiple pathways through programmatic interventions. These relationships contribute to the development of themes that aid our overall understanding of how women experience breast cancer in South Asia. For example, poverty, education, stigma, and the role of women may all have an influence on fear and fatalism about breast cancer. With the inability to afford services, lack of knowledge about options, a social environment that ostracizes women with breast cancer, and a belief that women's concerns are of less importance, it is not surprising that women are fearful and think there is nothing they can do about breast cancer. It also points out the importance of targeting multiple avenues for intervention: simply making women aware of a service does little to reduce fear when she cannot afford those services and does not believe she should use family resources for her own benefit.

Finally, this review illustrates the value of qualitative studies in providing the depth of understanding required to understand barriers women face to breast health care in South Asia, particularly given the weaknesses of Western-based health theory to explain health behaviors in these cultures. Studies using qualitative methods such as focus groups and in-depth interviews consistently generated more detailed information about barriers than studies using closed- or open-ended surveys (Appendix B). Quantitative studies are an important complement and follow-up to qualitative studies, which can then contribute to our understanding of the relative importance of barriers for different populations and confirm findings on a larger scale.

Conclusion

Overall, theoretical models which incorporate the concept of barriers, and general studies which have explored barriers to breast cancer care, particularly among South

Asian populations, provide important guidance in the development of culturally sensitive and ultimately effective programs to increase earlier diagnosis and treatment of disease. Further development of our understanding of the definition of barriers and the role of theoretical models in this process are important to improving the overall health of populations, particularly those most vulnerable. Interventions to address barriers should recognize that additional theoretical models might be required to appropriately deal with structural, social, psychological and organizational barriers.

Furthermore, the identification of these factors through qualitative research may serve as a starting point in the exploration of barriers to breast cancer care in any country with similar attributes, leading to a more in-depth study of issues through specially designed interventions. Ultimately, these efforts should positively influence women's quality of life and overall survival from breast cancer, and help bridge the health disparity now seen and expected to grow between high and low HDI countries.

CHAPTER 3

ISLAM AND ITS INFLUENCE ON BREAST CANCER CARE SEEKING AND TREATMENT OUTCOMES

Background

Religion is one social factor that affects the behavior of individuals, communities and countries to varying degrees, and as such has the potential to influence health in positive or negative ways depending on the message, interpretation, and context. Numerous studies have found a relationship between religion and religiosity and coping with illness, complying with treatment regimens, and ultimately health outcomes (Acklin, Brown, & Mauger, 1983; Ahmad, binti Muhammad, & Abdullah, 2010; Levin, 1994; Mitchell, Lannin, Mathews, & Swanson, 2002; Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006). A comprehensive review of studies found support for this relationship amongst such varied groups as Sephardic Jews, Benedictine Monks, Adventists, Mormons, Baptist clergy, and Zen Buddhist priests and suggested that this relationship may be causal. Furthermore, the author remarked that clinical and public health efforts have failed to incorporate these findings (Levin, 1994). An understanding of the role that religion may play as one component of the determinants of health may contribute to a more sophisticated understanding of how to improve health outcomes amongst those practicing a given religion.

Teasing out the role of a specific religion on health and specific health conditions is complicated by a number of potentially confounding factors, including the possibility that the practice of religion, regardless of what religion is practiced, may exert salutary

health effects on its practitioners (Levin, 1994). Nevertheless, the importance of medical anthropology and sociology in identifying factors that could be used to improve health interventions for specific populations has been noted, and the value of such recognition and incorporation into health interventions to individuals facing a range of diseases is encouraged (Smith, et. al., 2006).

The purpose of this chapter is to explore the potential role of Islam in influencing women's decisions to seek care for breast problems. The practice of Islam and its teachings as they relate to health and men's and women's roles in society will be explored, as well as self-reports from Muslim women in the literature about their experience with breast health services and breast cancer. This chapter will offer suggestions for incorporating findings into breast care programs that interact with Muslim women, particularly in low-resource settings.

Methods

I conducted a literature review to identify available published documents on the topic. Searches were conducted through the Arizona State University library system for Islam and Health, Islam and Women, Islam and Women's Health, and Islam and Breast Cancer. No limitations were made by geographic location or whether articles reviewed native or immigrant populations. Care was taken to limit findings to those which directly connected Islam and health, either through reference to specific passages of the Qur'an or Sunnas (Islamic holy teachings) or self-reports from Muslim women directly relating their beliefs and actions to Islam. I considered influences on Muslim women's health because of more general socio-cultural, economic, or environmental conditions, despite being important contributors to health, outside the scope of this paper. I reviewed

references for all selected articles and books for additional sources and incorporated findings into this review. I drew conclusions from common themes identified in the literature.

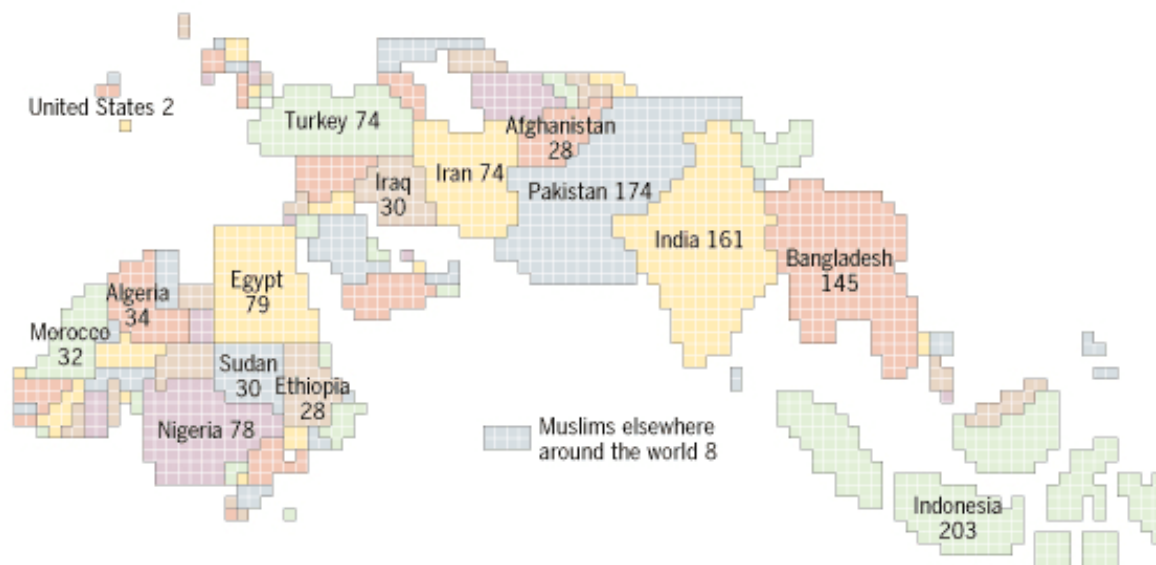
The Islamic Religion

Islam is practiced by over 1.57 billion people in the world (Pew Forum on Religion & Public Life.;Pew Research Center., 2009). Adherents of the religion Islam called Muslims, view its tenets as a guide to practice in both private and public life (Farizah Ahmad et al., 2010), but vary in their interpretation of Islam's holy text, the Qur'an. The Qur'an is believed to be the word of God as spoken to the prophet Mohammed from the years 610 to 632, and in combination with the Sunnas, or collections of written works about the actions of Mohammed, are the documents by which Muslims base their practice (Rahman, 1998). Islam is the youngest of all major world religions and draws from earlier religious texts such as the Bible (Christian) and Torah (Jewish), and believes that Mohammed is the last prophet of God. Within Islam, there are a number of major divisions, including Shi'a, Sunni, and Sufi, but in belief and practice Muslims share many similarities (Omran, 1980). Generally speaking, Muslims believe that God acts through natural causation and human volition to further God's purposes (Rahman, 1998). The word Islam means "submission" or "surrender" and being a Muslim means that one has committed him or herself to God (Sechzer, 2004).

Muslim populations exist throughout the world, but the largest populations are in the Middle East and parts of Asia (See Figure 1). The top ten Islamic countries in order of population are Indonesia, Pakistan, India, Bangladesh, Egypt, Nigeria, Iran, Turkey,

Algeria, and Morocco. Correspondingly, seven of these ten countries are considered by the World Bank to be low to lower-middle income countries (LMIC), defined as a country with a gross national income per capita under \$4,000 (“World Bank, World Development Indicators - Google public data,” n.d.). This represents approximately 56% of the world’s Muslim population. This is noted not to draw a correlation between Islam and development, but rather to put into context the economic challenges people in many Islamic countries face, which may also have a direct impact on health.

Figure 6: Weighted Map of the World's Islamic Populations*



*Numbers are rounded to the nearest million.

Source: Pew Foundation, 2009

Some predominantly Muslim countries are ruled by Islamic Sharia law, which is based on interpretation of the Qur’an, while others rely on varying forms of international law for their judicial systems. Those countries ruled by Sharia law (for example Saudi Arabia or Iran) typically take more conservative interpretations of the Qur’an and

consequently provide more rigorous constraints on the daily lives of their citizens (Rahman, 1998).

Practicing Muslims abide by five “pillars of Islam”. These include 1) a declaration that there is only one God and Mohammed is the last prophet of God, 2) prayer five times a day, 3) fasting from food, liquid or sex from sunrise to sunset during the holy month of Ramadan, 4) giving of 2.5% of one’s net wealth to the needy (called Zakat), and 5) pilgrimage to Mecca if one is able to afford the journey (Lawrence & Rozmus, 2001).

Muslims are described as putting their ultimate fate in the hands of God (Farizah Ahmad et al., 2010; Lawrence & Rozmus, 2001). While this can be interpreted as a passive approach to life, there is also a view amongst Muslims that God acts through the actions of human kind and thus, it is the responsibility of each individual to educate themselves about their options and act accordingly so that God may act through him or her. Education for both men and women is highly valued and stressed as an individual responsibility.

Islam also stresses the importance of doing well for others, in part evidenced by the giving of zakat but also as an act of daily life. At certain times of the year, such as during Ramadan, Muslims are especially observant of caring for those in need. Islamic holidays also come with restrictions such as fasting noted above, and limitations on travel outside the home. Furthermore, Muslims do not eat pork, require that animals be slaughtered in a specific manner called Halal, and do not use intoxicants including alcohol (Lawrence & Rozmus, 2001).

Health in Islam

The Qur'an places a great deal of importance on individual health as health allows one to obey God's commands. Health promotion is described as a primary focus of Islam, supported by a statement from Mohammed that "an ounce of prevention is better than a ton of treatment" (Athar, 1993). The body is considered a gift from God and should not be misused (Bahar et al., 2005). Both medical professionals and lay people are encouraged to know about health promoting and disease preventing behaviors (Athar, 1993). The Sunnas state, "There is a medicine for every ailment such that if the right medicine hits a corresponding ailment, health is restored by God's permission," (Rahman, 1998) which is interpreted to mean that Muslims must actively seek out effective treatments for health problems.

According to Rajaram and Rashidi (1999), "Health is a central concern in Islam...and members are encouraged to search for a cure through the teachings of the Prophet." (48). As such, there is an obligation among Muslims to stay healthy and seek care for ailments (K. Ahmad & Azzam, 1988). When Muslims do fall ill, they typically view their illness as the will of God. Illness may be a test of faith by God, or a punishment for bad deeds, and is a time in which Muslims will atone for their deeds and practice their faith with increased vigor (Errihani et al., 2008). The Qur'an notes that individuals who die of some diseases are martyred for their suffering (Rahman, 1998). The Qur'an recommends prayer for healing, which family members often perform with the patient. This provides a form of support for the individual suffering from disease, but in modern health care settings can make patient care difficult (Lawrence & Rozmus, 2001).

Though limited, there are some direct references to behaviors in the Qur'an which impact health. Eating in moderation is emphasized through the month of Ramadan in which Muslims fast during daylight hours, with the intent of teaching them restraint and empathy for the suffering of others (Maudi, 1960). A consequence of this behavior is limiting caloric intake, which may control weight and reduce the known health risks of being overweight or obese. Abstinence from alcohol is also prescribed by the Qur'an, which is known to reduce the risk of certain cancers, including breast cancer in women (Kalache, 1990).

The Qur'an also promotes regular physical exercise, citing walking, swimming and horse-back riding (Athar, 1993). Furthermore, the ritual prayer conducted by Muslims five times per day was found by one study to burn a total of 340 calories when done as prescribed (Athar, 1993).

Islam encourages the use of available resources, including modern science and technology, so long as it serves a moral purpose. Thus, "Western" or allopathic medicine is not discouraged (Athar, 1993). However, other aspects of the delivery of allopathic medicine may create a barrier to its delivery, which I explore in the context of breast cancer later in this chapter.

The practice of medicine is one of the ways in which people may do well for other humans. Throughout history, Islam has placed great value on doctors and has prioritized the creation of medical centers to serve every member of the community. Ibn Sina (d. 1037) is a famous Islamic doctor who focused on the mind-body connection and ability to affect cure through willpower; or conversely to induce sickness through the belief that

one has been afflicted with a malady or curse (Rahman, 1998). In this respect, Islamic medicine is quite progressive in its recognition of psychological influences on health.

“A Muslim woman should not expose their body to any man except their husband, father, brothers, or uncles. We believe that the woman’s whole body is sacred and should not be exposed. The only exception...a health problem. We strongly believe that Allah will be merciful to women who are modestly clad.”

--Muslim woman quoted in Underwood et al., 1999, p. 288

Women and the Qur’an

The Qur’an is clear that, in the eyes of God, men and women are equal. However, in daily life, men are the caretakers of women and family members advise women to obey their husbands and senior male relatives. Women who do not obey their husbands can be forced to do so according to the Qur’an (Bahar et al., 2005). The Qur’an also provides specific guidance for women in terms of modesty and dress. Women are requested to dress modestly, including covering themselves from head to toe when outside the household after they reach puberty, with only the face and hands minimally exposed (Lawrence & Rozmus, 2001; Sechzer, 2004; Underwood, Shaikha, & Bakr, 1999). As such, women are not allowed to use a male doctor unless they cannot find a doctor of the same gender (Athar, 1993), and are not permitted to be alone with a man who is not her husband or a close relative (Lawrence & Rozmus, 2001). In practice in some Islamic countries and communities, family and community members expect women to stay within the confines of the home unless escorted by a male head of household. Amongst immigrant populations to the US a family’s fear of becoming “Americanized” and losing touch with Islamic principles keeps women isolated (both self-imposed and by

other family members) and sometimes out of touch with important health (and other) information (Rajaram & Rashidi, 1999).

Islam may have positive impacts on women's health in that it encourages women to be educated, to value their role in the community, and to maintain healthy behaviors. Women are typically encouraged to be active within the community and express their views (Athar, 1993; El-Safty, 2004), though this may come into conflict with more conservative views, or what are described as misinterpretations of Islam which discourage women's active involvement in the community (Sechzer, 2004).

Modesty by and role expectations for Islamic women may also interfere with health in circumstances where it is required to see a male doctor and/or expose parts of her body. She may be uncomfortable or unwilling to do so, or a family member may discourage this behavior, resulting in a lack of care. Furthermore, she may not play an active role in her own care if she is not free to visit health facilities as needed during illness.

Breast Cancer Care in Low-Resource Islamic Countries

As described in Chapter 1, women presenting with breast problems in low-income countries often do so with metastatic, or incurable, disease. Studies of Israeli and Malaysian Muslims found that these women suffered advanced breast cancer at significantly higher rates than other religious groups within their respective countries, which was attributed to delayed care seeking behaviors (Azaiza & Cohen, 2008; Yip, 2009). It is potentially meaningful to understand whether Islam plays a role in delaying care for breast cancer.

Contemporary Muslim Women and Breast Cancer

While limited in number and lacking in theoretical grounding, selected studies from around the world have looked at the role of Islam on the uptake of breast cancer screening behaviors such as breast self-exam, clinical breast exam (exam by a doctor) and mammography and views about breast health and a diagnosis of breast cancer. Overall, Islam is not generally in conflict with modern health systems, yet societies practicing Islam often present with some unique circumstances that may prevent women from getting the best care for their health problems. Most of the views expressed by women in these studies correspond with the basic tenets of Islam, though some deviations and alternate interpretations exist. A number of themes resonate regardless of geographical location of the study groups, which I explore, below.

First, Muslim women in Morocco, Malaysia, Israel and Iran expressed views that a diagnosis of cancer, including breast cancer, was either a test of faith from God, or a punishment for past wrong-doing (Ahmad et al., 2010; Azaiza & Cohen, 2008; Errihani et al., 2008; Taleghani, Yekta, & Nasrabadi, 2006). In either case, the outcome was up to God to determine, and God would favorably view the process of enduring and fighting the disease. These women found peace through surrendering their fate to God, and in this sense, their religion was coping mechanism for reducing stress, not unlike other religions.

Women expressed that community members viewed a diagnosis of breast cancer, or simply the appearance that a woman may have breast problems, unfavorably, and that friends and relatives may shun them. Women greatly feared a loss of femininity from mastectomy, and felt that their husbands may be justified in leaving them if they cannot fulfill their roles as a Muslim woman (Azaiza & Cohen, 2008). In a study of men and

women diagnosed with cancer (including breast cancer) in Morocco, over 100 people were divorced as a direct result of their cancer diagnosis (Errihani, et. al., 2008). Interviews with women in Bangladesh have also revealed this phenomenon in the context of breast cancer (Story, 2012).

Modesty prescribed by Islam and discomfort with breast exam by a doctor were expressed by many Muslim women. Amongst a small sample of Iranian women asked about breast exam, over half expressed that they weren't sure or that it was against their religion to be examined by a male doctor, and almost 60 percent preferred to be seen by a female doctor (Montazeri, Haji- Mahmoodi, & Jarvandi, 2003). In Israel Muslim women expressed similar sentiments stating "...to ascribe an illness to my breast and to expose it to doctors...many women will feel embarrassment," and the authors go on to state that "...a woman may not expose her body to a man," and that "it should be done only if it is not possible for her to be examined by a female doctor" (Azaiza & Cohen, 2008).

Amongst a small sample of Muslim women focus group members in the US, modesty and particularly the difficulty in seeing a female doctor was cited as a reason for not routinely seeking breast cancer seeking despite availability (Underwood et al, 1999).

Women diagnosed with cancer in Morocco responded by becoming more modest in their dress and increasing religious practice and prayer (Errihani, et. al., 2008).

In a positive light, Muslim women in Israel expressed that breast-feeding, a known protective factor for breast cancer, was supported by Islam, and that breast-feeding for 30 months was encouraged. Furthermore, one woman noted that "God blesses women who give birth to many children, so giving birth and breast feeding can reduce the chances of cancer" (Azaiza & Cohen, 2008). Despite expressed modesty, women in a

variety of countries viewed seeking knowledge about breast problems and diagnosis and treatment for such as an obligation. In this sense, women were able to overcome some of the potential negative care-delaying behaviors of women with breast cancer.

The theme of responsibility for one's health came up in discussions with Muslim women in Israel and immigrant women in the US (Azaiza & Cohen, 2008; Underwood et al., 1999). Women felt it was their responsibility to take care of their bodies until judgment day, that their bodies were a gift from God, and expressed that if more women followed the religion (of Islam) that "they would pay more attention to their health and do everything to take care of it" (Azaiza & Cohen, 2008). These same women expressed that their religion obliged them to undergo medical treatment and tests, regardless of the physician's gender (Azaiza & Cohen, 2008).

Implications for Breast Care and Breast Cancer Programs Globally

Overall, Islamic teachings are supportive of caring for one's health, be it in a preventive or active diagnosis and treatment modality. Numerous citations from the Qur'an support this idea and may be used in health communication activities among Muslim populations for many diseases. Furthermore, the input of Muslim women and their experiences dealing with a variety of health systems globally contribute to a number of recommendations for improving breast care for Islamic women before, during, and after interaction with the health system.

First, incorporating messages from the Qur'an that support active seeking of health services for breast problems may increase the likelihood that women will seek out such services. Rajaram and Rashidi (1999) state that "Tailoring health promotion messages about breast cancer screening to religious and socio-cultural beliefs will go a

long way in increasing breast cancer prevention awareness among immigrant Asian-Islamic women” (Rajaram & Rashidi, 1999, 56). Specifically, the idea that women should educate themselves about their health and take action to allow God to work through them may resonate with Muslim women.

“...the failure of many breast cancer screening programs to accommodate the beliefs, values, and customs of Muslim women significantly affected compliance with recommendations for breast cancer screening. As a result, breast cancer screening was not routinely performed by the Muslim women...”

-Underwood, et al., 1999

Given reluctance to expose one’s body, and the difficulty some women may face seeking out preventive screening, two recommendations are put forth. First, while breast self-exam has been questioned as an effective means to reduce breast cancer, as suggested by Montazeri, et al. (2003) it may still be an important element in countries where male doctors are the norm and women are, for religious or other reasons, uncomfortable exposing their breasts or having a male-conducted breast exam. Rajaram and Rashidi (1999) suggest incorporating breast self-exam (or self-awareness) into ritual cleansing performed by women after completing menstruation and before prayer. This simple measure may be particularly effective in low resource settings where women do not or cannot visit a doctor regularly for a clinical breast exam or mammography.

Additionally, as suggested by Underwood, et al. (1999), making female doctors and staff available for Muslim women, or creating a “woman only” day for breast screening would contribute greatly to comfort levels amongst Muslim women. Offering such services at times that are more convenient for women with family responsibilities

(i.e., after lunch) and with sensitivity to Islamic holidays when Muslims limit unnecessary travel may increase women's ability to access services. During visits with health providers, explaining the process and need for exam, allowing women to keep on some of their clothes (such as their veils), and allowing other female family members to be present at the exam may all improve Muslim women's perception of breast exam and increase use of such services. Lawrence & Rozmus (2001) suggest that health care settings should provide copies of the Qur'an for patients and be aware of dietary restrictions and the need for prayers, sometimes with other family members present.

Care providers must also be sensitive to the fact that a diagnosis of breast problems or even the perception that a woman may have breast problems can be very detrimental to a Muslim woman, as in the example of divorce noted by Errihani, et al. (2008). Counseling in the delivery of negative findings with use of references to Islam may be comforting and helpful for Muslim women and their families.

Given that Islam encourages a number of positive factors for reducing breast cancer (weight control, exercise, breast-feeding and child rearing), each of these may be reinforced in breast cancer awareness campaigns and during patient encounters with the health system. As Rajaram and Rashidi (1999) state, "Incorporating...Islamic health-related messages in breast cancer screening educational efforts is essential in increasing awareness and practice of breast cancer screening techniques among Asian-Islamic women." This likely holds true for Muslim women around the world.

Islam, however, is just one of many contextual factors that influence health around the world. To view Islam as an independent factor affecting health would be to misunderstand how many socio-cultural, economic, environmental, and political factors

interplay to create conditions of health in different contexts. As illustrated by Bottorff, et al. (1998) women from various parts of South Asia living in Canada, and representing Hindus, Muslims, Sikh and other religions have similar attitudes and potential barriers towards breast health practices which, when understood, may have broader implications for breast care programs. Rajaram and Rashidi (1999) also cite numerous other issues that Asian-Islamic women face which may discourage them from receiving needed health care: issues such as deference to physicians, difficulty communicating effectively with medical providers and patriarchal beliefs not necessarily prescribed by the Qur'an, but rather considered a form of misinterpretation of the Qur'an (Siddique, 1988). These are each examples of "determinants of health" that are not a direct result of Islam, but have an impact on the identification and effective treatment of diseases such as breast cancer. The vast economic disparities women in many Islamic countries face, as well, contribute greatly to women's knowledge of and access to quality care. Furthermore, Azaiza and Cohen (2008) raise an important point that culture and religion are dynamic and that health messages must be adapted to changing information and attitudes over time. Biomedical information about breast cancer and its risk factors and treatment options is rapidly changing, bringing new opportunities for integrating this information with cultural beliefs and norms. Considering the impact of Islam in the context of these other factors is essential to developing a comprehensive and effective breast care program in both developed and developing countries.

It is clear, however, that there are specific elements of Islam, which when understood and acknowledged on their own can greatly contribute to creating more effective health education campaigns and interventions for individuals, families, and

potentially countries. Furthermore, regardless of the broader potential applicability of themes such as modesty and deference to elders that may exist in other cultures, active acknowledgement of these concerns directed at the individual Muslim woman in the context of Islam has great meaning and potential influence. Unfortunately, a very limited number of researchers (Lawrence & Rozmus, 2001, for one) have attempted to incorporate theoretical models into their understanding of Islam and health and as such, it would be beneficial to our understanding in the future to explore their use.

Ultimately, it is the aim of breast care programs to reduce the pain and suffering of women and their families because of breast cancer. Thus, identifying and addressing the factors that hinder this aim is an important process. In light of the dearth of information and extent of misunderstanding about Islam expressed by many researchers (Lawrence & Rozmus, 2001; Sechzer, 2004; Underwood et al., 1999) and the fact that Muslim women in many countries suffer to a greater degree from breast cancer (in both incidence and severity) than some other ethnic groups, the continued exploration of the role of Islam on women's health over time is warranted.

CHAPTER 4

BREAST CANCER IN BANGLADESH

The Country

Bangladesh is located in Southern Asia, between India and Myanmar, and borders the Bay of Bengal to the south. It is the seventh most populous country in the world; a country of nearly 160 million people (approximately half the population of the US) in an area half the size of Italy or a mid-sized state in the US such as Iowa. Over 70% of the country is considered rural, although population density is high throughout the country (CIA, n.d.). The country has six Divisions, which are further divided into Districts (Figure 7). The Khulna Division, which is home to study participants discussed in

Figure 7: Bangladesh by Division



Chapter 6, has a population of 15.5 million (Bangladesh Bureau of Statistics, n.d.).

Over 89% of Bangladeshis consider themselves Muslim, making Bangladesh the third largest Muslim-dominated country after Indonesia and Pakistan. Approximately 45% of the population works in the agricultural sector.

Bangladesh is a lower-middle income country (LMIC), defined by the World Bank, and a medium Human Development Index country (HDI)

according to the United Nations Development Programme. About 40% of the population is underemployed; many participants in the labor force work only a few hours a week, at

low wages (CIA, n.d.). Approximately 60% of women are illiterate (CIA, n.d.) and 27% of the population is undernourished (The World Bank, n.d.-c).

Government and non-government rural health clinics provide primary health care, and provide referrals to the District or Division level for secondary or tertiary level care. Individuals can rarely receive tertiary health care at the Division level or lower due to a lack of trained health care providers, treatment facilities, and patient resources. In the case of radiation therapy, resources are significantly lacking. There are approximately eighteen functional radiation therapy units in Bangladesh; only nine units were available as of 2013 in government medical college hospitals (Uddin, Khan, Islam, & Mahmud, 2013), with the remaining owned by private facilities. An estimated three-hundred such units are needed (“Advancing cancer care in Bangladesh - Fogarty International Center @ NIH,” n.d.). Radiation therapy is an important form of breast cancer treatment for lowering the chance that breast cancer will come back once surgically removed, to treat cancer that has spread to other areas, and for palliative care. Individuals seeking treatment such as that found in high-income countries must travel to the capital city, Dhaka, or leave the country if resources allow. For most rural-dwelling people in Bangladesh this is simply not feasible, leaving them to rely on available local services. Many rural people first or exclusively seek care from a variety of alternative forms of care for health problems, including ayurvedic, homeopathic, spiritual, and self-proclaimed healers (Ahmed, Hossain, & Chowdhury, 2009; Claquin, 1981).

Total health expenditure in Bangladesh as a share of GDP is one of the lowest in the region (Ahmed et al., 2015). Government facilities charge nominal fees for admission, but individuals pay for the majority of medical expenses (diagnostics, surgery,

medications, etc.) out-of-pocket. Furthermore, studies show that health providers often ask patients to pay more than the standard fees for services in order to receive priority treatment (such as a bed, or to see the doctor sooner), for cleaning, or to access to scarce medications or basic nursing (Akter & Islam, 2006; Claquin, 1981; Zaman, 2004). Individuals, thus, carry the burden of medical costs in Bangladesh, particularly for complicated diseases.

Public hospitals are frequently overcrowded, unsanitary, and lacking in essential resources including basic equipment and essential drugs. Patients can be found sleeping on the floor or sharing beds, and report poor treatment by hospital staff and physicians (Akter & Islam, 2006; Claquin, 1981; Zaman, 2004). Private hospitals with better resources are growing in number, but are financially out of reach for most Bangladeshis.

Modern health services for breast cancer are severely lacking, particularly in rural areas (Haque et al., 2015; Hossen & Westhues, 2011; Zaman, 2004). The doctor-patient ratio in Bangladesh is 1:3,300 people (The World Bank, n.d.-b) with 52% of doctors concentrated in urban areas (including private hospitals). One report estimated a ten-fold difference, with one doctor for 1,500 people in urban vs. 1:15,000 in rural areas (Mabud, 2005). This leaves rural doctors to manage extremely high caseloads. As in high-income countries, physicians are often unwilling to take posts in rural areas due to the lack of additional opportunities for private practice and preference for the conveniences of an urbanized area. Female doctors are even scarcer. Of all medical graduates since 1971, only 23% are female (Bangladesh Department of Health and Family Welfare personal communication).

Gender, Family and Social Roles in Bangladesh

Bangladesh is a country enmeshed in strong gender and social roles. Among strict Muslim families, women observe purdah, or seclusion, inside their homes. Throughout Bangladesh, a woman marries and produces offspring at an early age in comparison with Western standards. Inability to bear children in the Muslim world (a frequent complication of breast cancer treatment) often leads to questioning by family members about her gender identity and to marital instability (Inhorn, 2003). Married women typically live in their husband's home with the mother and father in law, and recognize the authority of their new family. Notions of privacy, individuality, and independent decision-making are not common in Bangladesh. As a familial and patriarchal society, the head of household usually has the final say. In a study of Egyptian (largely Muslim) reproductive choices, it was found that women who live with an extended family have less control of resources and decision making power than those who live in a nuclear family (Yount, 2005). Pasick (2009) notes that common health theory constructs such as individual intention do not hold up when tested with non-white, underserved populations who involve extended family members in decision making processes (i.e., "relational" cultures), and "provided little guidance in the design of measures and messages" for cancer screening.

Breast Cancer in Bangladesh

Epidemiology: Incidence, Prevalence, Mortality, Delay

While breast cancer has the attention and research dollars of the developed world, lower and middle income countries (LMIC) are only beginning to recognize the extent and impact of the disease (Bray et al., 2012, 2013). In LMIC, infectious diseases such as

cholera, tuberculosis, and HIV/AIDS have been the focus of wide-scale interventions, with corresponding reductions in unnecessary suffering and death. However, as populations live longer and adopt behavioral patterns such as delayed child bearing, intake of fatty foods, and reduced activity, the burden of cancers grows (Torre et al., 2015). With a population of 160 million people in Bangladesh, this burden is and will become an even greater stressor on health care systems. While cancer and death registries are inadequate to provide confident reports, it is estimated that there are approximately 15,000 new cases of breast cancer in Bangladesh annually, and over 53,000 women living with the disease at present (“Fact Sheets: Bangladesh Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012,” n.d.). Furthermore, while women in higher income countries are diagnosed at earlier stages and can typically expect to survive a diagnosis of breast cancer, the majority of women in rural Bangladesh present with regionally advanced breast cancer or worse (Story et al., 2012), and almost 50% of women diagnosed in Bangladesh die from the disease (“Fact Sheets: Bangladesh Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012,” n.d.). Women who do not present at a formal health service provider comprise a significant, though uncounted, number of women in Bangladesh and likely other LMIC (Story et al., 2012).

Barriers to Breast Cancer Care-Seeking in Bangladesh: Formative Research
In Bangladesh, women with breast cancer are sometimes kept isolated from other family members for fear the cancer is contagious. For example, relatives may not want a woman with breast cancer in their home for visitation. Breast cancer has been described by some focus group members as a “curse from God” or a “plague” that visits a family

for wrong-doings (Story et al., 2012). It thus carries with it a judgment on not only the woman but also her whole family. Informal discussions with village women in the Khulna District of Bangladesh revealed that women did not come forward for care due to feared stigma and ostracism by the community and family. In the extreme, women feared expulsion from the family or even for their lives. In one known case, it was unclear whether a woman committed suicide or her family murdered her shortly after her diagnosis of breast cancer. Thus, there appears to be an important link between stigma and feared or actual violence (including physical and emotional violence, as well as neglect) experienced by women suffering from breast problems in Bangladesh.

The role of Bangladesh's health system, systemic poverty, environmental and infrastructure barriers in seeking and receiving breast cancer care are also important contextual elements in Bangladesh. The dearth of female doctors in a country where it is improper for any male but the husband to touch a woman makes it difficult or impossible for women to get proper exams. Only the very wealthy in Bangladesh can afford to leave the country to seek modern medical care. Regular devastation due to flooding and typhoons amplify the effects of already inadequate infrastructure. Thus, the view that breast cancer is a "death sentence" is not far from the truth for some women.

The following chapter, Chapter 5, will explore theoretically based constructs that help explain violence against women, with a focus on constructs with application to internationally based populations in low-resource settings. Constructs that may explain why women with a life-threatening disease in Bangladesh report violence as a reason for not seeking care are of particular interest for this dissertation.

CHAPTER 5

COMMON THEORETICAL CONSTRUCTS ON VIOLENCE AGAINST WOMEN: IMPLICATIONS FOR THE STUDY OF BREAST CANCER IN BANGLADESH

Background and Introduction

Chapter 4 established that some women in Bangladesh have reported extreme forms of stigma and abuse in relation to their breast cancer or suspected breast cancer diagnosis. An examination of theoretical perspectives on violence against women and the common constructs they incorporate is undertaken in this chapter to explore potential explanations for these findings. This chapter concludes with a discussion of how findings may influence further research on the relationship between stigma, abuse and breast cancer among women in Bangladesh.

Existing theory ranges from psychological and biological explanations for why individuals commit violence to cross-cultural explanations incorporating multiple levels of influence. For the purposes of this chapter and in the context of this larger dissertation, theories that seek to explain differences in societal or cross-cultural violence are of primary interest, particularly those that can help explain violence experienced by women in low-resource settings. As a result, discussion of psychological and biological theories of violence is beyond the scope of this chapter.

Theories of violence fall into two general camps: gendered and non-gendered. Feminist theory and theories drawing on societal male dominance (patriarchy) as their core component are “gendered” theories. I define patriarchy, for the purposes of this paper, as social systems that promote male dominance and authority in both private and

public life, and subsequently view women as inferior. Gendered theories place a primacy on the role of gender and particularly the influence of societal male dominance on violence against women. Encompassing the social roles and cultural expectations that individuals play out as a self-identified male or female, gender is here distinguished from the biological designation as male or female (i.e., sex). The choice of this terminology highlights the most important debate among theories to explain violence against women, namely, whether gender and the hierarchies created by a male dominant society should be the primary focus of theory. Later feminist theories such as those proposed by Hunnicutt (2009) and Anderson (2005) incorporate elements of non-gendered theory, but maintain gender as a central organizing component. Gendered theories have their origins in the feminist movement of the 1970s (Gelles, 1980; Hunnicutt, 2009). Although earlier theory explained aggression and violence in societies (Albert Bandura, 1973; Dollard, Miller, Doob, Mowrer, & Sears, 1939), feminist views on patriarchy as the root of violence against women were originally asserted through the work of scholars such as Brownmiller (1975) and Dobash & Dobash (1979). Gendered theory and the use of the term “patriarchy” lost momentum in the 1980s, and then gained ground again in the late 1990s as researchers uncovered the varieties and complexities of violence against women because of gender hierarchies both domestically and abroad. Today, gendered theories continue to be an important addition to the understanding of violence against women. I include selected contributions to feminist, gendered theory throughout this chapter.

The second broad category, therefore, is theory that does not explicitly consider gender to be an important predictive variable. These theories, referred to here as “non-gendered” theories, consider other sociodemographic factors more important to

explaining how and why women experience violence. Gender and gender inequality are still variables within these theories, but not the central organizing feature. Non-gendered theories grew from a variety of disciplines and found widespread appeal when studies began to show that, at least in the US, women are as likely as men to engage in domestic violence (Murray A. Straus, 1979). Among these theories are those that were not originally designed to explain violence against women, which expand the use of these theories and broaden the understanding of this event.

The extent of debate about theories on violence against women can be explained, in part, through the wide range of disciplines represented by scholars in the field, typically aligning with the gendered or non-gendered view of violence. In addition to feminist scholars, sociologists, anthropologists, psychologists, public health, and criminal justice experts have contributed their perspectives and research findings (Jasinski, 2001). The majority of early studies of violence focused on Western populations, which led to generalizations that did not always apply in multi- or cross- cultural settings. Cross-cultural scholars have since conducted studies contributing to the understanding of theory that can account for observations around the globe (Archer, 2006; Gelles & Cornell, 1983; Levinson, 1989).

Despite this major divide in theoretical perspectives and the many epistemological differences, there are important common constructs of particular importance to the understanding of violence against women in low-resource settings. These constructs include the role of patriarchy, threats to traditional gender identity, conflict as a source of violence, access to resources, status inconsistency and social change, social acceptability of violence, and violence to maximize reproduction. These constructs will each be

discussed, noting major contributions and debates, as well as their importance to this dissertation.

Definition of Violence and Terminology

Before themes are discussed, a note on the use of the term “violence” is in order.

The United Nations developed the broad definition of violence against women used throughout this dissertation in 1993. The definition states that violence against women includes “any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivations of liberty, whether occurring in public or private life” (UN General Assembly, 1993). The definitions of violence, however, may differ by theoretical perspective, and this difference may be critical to understanding the applicability of a given theory to this broader view of violence. Gelles and Cornell (1983) note that there is “enormous variation” in the definitions of family violence (which includes violence against women), and that this has made cross-cultural analysis of data difficult to accomplish. Some researchers have hypothesized that the type of violence committed is dependent on the offender and their motivations (Johnson, 1995, 2001), but no consensus has been reached on this issue.

Furthermore, terminology to describe violence against women varies by theoretical perspective and reveals important distinctions between theories. “Violence against women” is the phrase used by feminist scholars and activists to emphasize the specific act of men’s violence toward women. “Wife abuse” or “battered wives” are other phrases within this perspective. Other descriptors, however, will be used, depending on the theoretical perspectives and constructs being discussed. “Spouse abuse” and “intimate

partner violence” are other more gender-neutral phrases used by some theorists of non-gendered or hybrid theories. “Family violence” is an additional non-gendered phrase used to cover the various types of violence that occur within the family unit. I make an effort in this chapter to note the varying definitions of violence, and to use terminology reflecting various theoretical perspectives, where appropriate.

Key Constructs in Violence against Women Theory

Gender (Societal Male Dominance/Patriarchy/Feminist Theory)

The feminist movement gave rise to scholarly efforts to explain violence against women in the late 1960s and early 1970s. Various writers, activists and scholars are cited for stressing the extent and importance of violence against women, among them radical feminist Susan Brownmiller and her book *Against Our Will: Men, Women and Rape* (Brownmiller, 1975 cited in Hunnicutt, 2009), co-authors Dobash and Dobash (1979), who made a strong case for patriarchy as the cause and perpetuation of violence against women, and widely published descriptions of battered women’s lives (Gelles, 1980). Patriarchy as a theoretical concept explained violence against women as a tool consciously used by men to socially control women (Hunnicutt, 2009).

Compelling counter arguments to patriarchy as an explanation for violence against women were based on data from a survey called the Conflict Tactics Scale developed by Straus (1979) (Dutton 1994), showing nearly equal amounts of male and female violence in the home (Murray A. Straus, 1979). This led to the concept of “gender symmetry” in the field of violence, in which gender was not believed to be the main influence on violence. Ten years later, Levinson, in his book on cross-cultural family violence, called patriarchal theory on violence “less of a social science theory than a

political agenda, associated with the feminist perspective on family violence" (Levinson, 1989, p. 16). However, he also concluded that violence occurred more frequently in countries in which husbands have economic and household decision-making power and where divorce is more difficult for women than for men. Dutton (2005) asserted that the gender paradigm had resulted in misdirected social and legal policy, misinformed custody assessors, police, and judges, a disregard of data sets contradictory to the prevailing theory, and mislead therapeutic change for perpetrators of violence. He also stated that feminists generalized about violent men, men in general, and ignored female pathology (Dutton & Nicholls, 2005). Feminist scholar, Hunnicutt (2009), agreed on some of these points, noting that patriarchy has been conceptualized as a "fixed and timeless structure that obscured differences in context and reduced all gender relations into one form" (p. 558). She observes that not all men in patriarchal societies are violent, and in fact, patriarchal societies can exist without the use of violence. Additionally, she cites studies finding that it is usually the least powerful men in society who use violence. The term "patriarchy" became less commonly used, and replaced by such terms as gender inequality or male dominance (Hunnicutt, 2009).

Many feminists, however, felt that arguments against patriarchy from a non-gendered perspective shifted resources and attention away from the issue of violence against women, hurting women in the process, and that non-gendered theories do not explain the behavior of men and women in relationships. Critics of the Conflict Tactics Scale, the major source of ideas about gender symmetry, said that it ignores "the contexts, meanings, and motives of both men's and women's violence" (DeKeseredy & Dragiewicz, 2007).

Because of the application of feminist theory globally over time and in response to its critiques, feminist theory evolved to explain a variety of conditions and in the process integrated contributions from researchers in other fields. Anderson (2010) provides an example of a revised “structural theory of patriarchy.” Anderson asserts that that identifying an individual’s social location in hierarchies of gender, race/ethnicity, and class is important to consider in violence research for two reasons. First, social location shapes the stressors, resources, opportunities, and constraints that people experience. Second, social location influences the attributions of violence that victims, perpetrators, and bystanders make, resulting in variable outcomes for similar acts across contexts. Anderson (2005) notes that “...men and women are located differentially in the social world because of gender inequality and thus they experience IPV differently. The location of the perpetrators and victims who experience the acts is gendered” (p. 734).

Social role theory is a structural theory with social psychological and feminist influences. Archer notes that social role theory also includes mediating variables between structural variables such as gender empowerment and individual actions, which strengthen the model. For example, attitudes toward abusive behaviors (representing belief systems) contribute to cross-national differences in female victimization. This model is especially useful for understanding why research conducted in western nations has not supported a gendered theory of violence, since data reflect men and women from individualist and highly empowered populations. Anderson (2010) describes Archer’s study as an example of gender being theorized from a structuralist perspective, which is better able to explain variation in violence.

In a study of 16 countries, the social role theory was able to explain cross-national and cross-cultural data, showing *women* were more likely to engage in partner violence when they came from more individualistic versus collectivist cultures and were more empowered (as measured by the Gender Empowerment Index or GEM)(Archer, 2006).

Hunnicut (2009) shares structuralist views in her description of “degrees of patriarchy,” another example of a revised view of patriarchy’s influence on violence against women. From her perspective, gender continues “as a central organizing feature” with a hierarchy of social systems and social arrangements that maintain male dominance (p. 554). While Hunnicutt acknowledges that, within the realm of domestic violence, men and women may actually commit similar amounts of violence, she also notes that across all types of violence men commit more violence than women do, and that the types and impacts of violence play out very differently depending on gender. As a result, she believes that violence is a gendered event.

Hunnicut’s suggestion for a revised theory of patriarchy includes five parts. First, she believes a theory of violence against women must reflect different types of patriarchies around the world (or “varieties of patriarchy”), both as they currently exist, and as they change over time, and that legal systems vested in patriarchy do not often hold men accountable for violence.

Second, Hunnicutt believes a revised theory must account for how society situates men in patriarchy. She notes that some men benefit more under patriarchy than others do, and that their placement in the larger context of patriarchy helps explain why some men are violent and others are not.

Third, theories of patriarchy must recognize that patriarchy can continue to exist despite structural gains in gender equality. Women may make gains in society, but still be required to act by the rules created by a patriarchal society.

Fourth, a theory of patriarchy must be understood within other forms of hierarchy and domination. Hunnicutt notes that “patriarchal systems are bound up with other systems of domination” (p. 563) including older over younger, men over women and men over men, whites over people of color, developed countries over lesser-developed countries, and even humans over nature. She also points out that these systems of domination are adopted by families and by religious and state institutions, and that women also benefit from and thus have an incentive to uphold these systems of domination when they have power. As a result of the interconnectedness of these systems, a single person may be oppressed, an oppressor, or both at the same time.

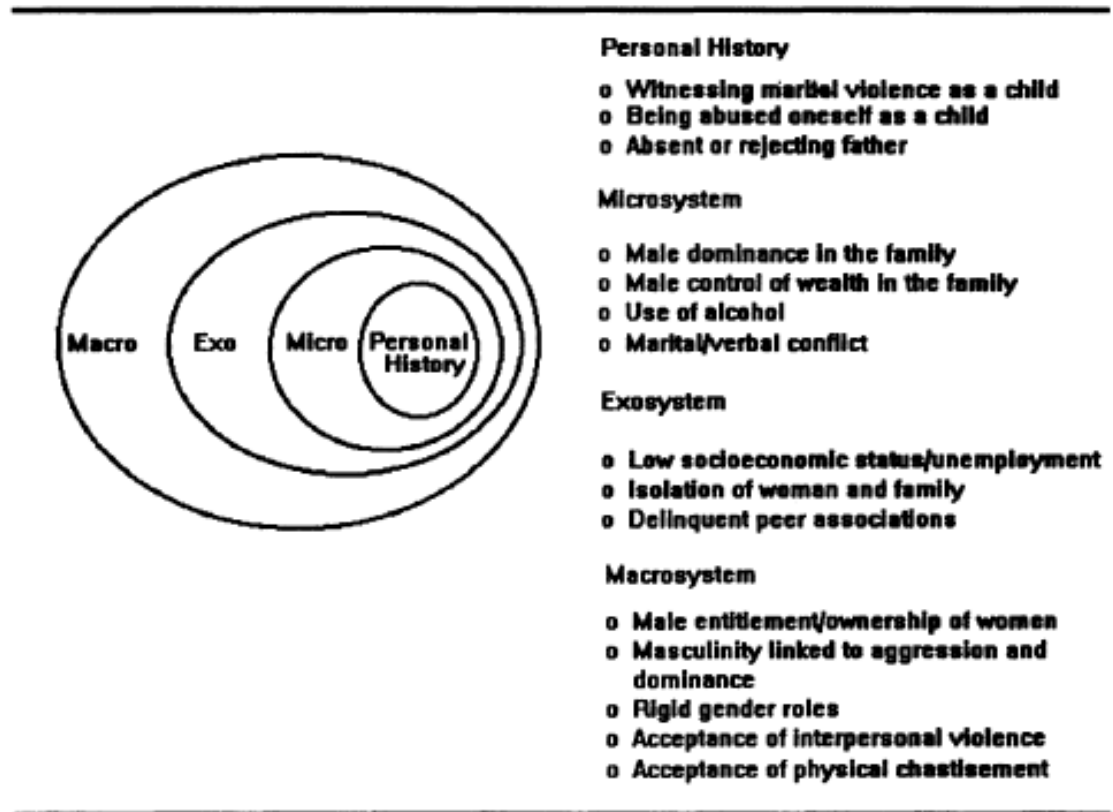
Fifth, a theory of patriarchy must incorporate “labyrinths of power dynamics” where both men and women have different levels of power. Early views of patriarchy cast men as desiring power over women and women as helpless victims. This simplification ignored the fact that individual men have varying levels of power, and women have degrees of power, some of which results from their associations with men. Hunnicutt illustrates this point through an example of women practicing Purdah in Muslim and Hindu cultures. Seclusion protects women from harm, but if women choose to violate these norms, their protections are lost. Furthermore, Hunnicutt notes that not all women are victims of violence because they are women. There are other “labyrinths of power dynamics” that lead to victimization (e.g., race, class, religion) (p. 564).

Heise's ecological model of violence (Heise, 1998), developed a decade before Hunnicutt's work, incorporates multiple constructs discussed later in this chapter, but clearly acknowledges the role of societal male dominance, stating:

“Any analysis of violence must recognize the primacy of culturally constructed messages about the proper roles and behavior of men and women and the power disadvantage women bring to the relationship by virtue of their lack of resources. Male dominance is the foundation for any realistic theory of violence, but experience suggests that as a single factor explanation, it is inadequate” (p. 263)

Her model grew from international research (including Levinson's) suggesting that sexual economic inequality, male domestic authority, divorce restrictions for women, and societal attitudes towards violence were the strongest predictors of wife beating. Heise's model reflects a number of theoretical constructs this chapter will discuss in more detail in the following pages. The model, shown in Figure 6, has been widely cited, used by the United Nations to support the Declaration on the Elimination of Violence Against Women (UN General Assembly, 1993), and supported by research conducted on domestic violence in Asian countries (Brown, 2014). Nevertheless, it has been suggested that additional empirical information and theory are needed about the importance of factors included in each level of Heise's model, how they are related, and how they influence women's risk of violence (Bates, Schuler, Islam, & Islam, 2004).

Figure 8: Factors Related to Violence against Women at Different Levels of the Social Ecology (Heise, 1998)



Threats to Traditional Gender Identity

Traditional gender roles are typically tied to the gendered theory of patriarchy, where men are the heads of household and expected to provide for the family financially. Some scholars suggest that the division of labor (men as breadwinner and women as homemakers) created expectancies for men and women that became stereotypes of typical male and female behavior (Eagly, Wood, & Diekmann, 2000). Families pass on these stereotypes through generations, thus perpetuating the behaviors. Stereotypical masculine behaviors include the use of aggression, whereas the feminine role inhibits aggressive behavior (Archer, 2006). Violence, thus, has different meanings for men and

women. Violence is one way in which men perform or demonstrate masculinity, particularly when their gender ideology is threatened (K. L. Anderson, 2010).

The idea of threats to traditional gender identity as a trigger for violence has been theorized amongst both gendered and non-gendered scholars, and is thus here discussed separately from patriarchy despite its similarities.

As noted by Hunnicutt (2009), a strong masculine identity can also act in a protective manner toward women in the form of chivalry. Thus, a heightened self-identification with masculinity does not necessarily equate to violence unless threatened.

This finding is also in line with the social interactionist perspective on violence, which identifies threats to identity as a precursor to violence. According to this theory, researchers Felson and Tedeschi view violence as a form of coercion used to gain compliance, redress injustice, and to assert and defend identities. In patriarchal societies where men are expected to appear “strong, fierce, and courageous” (Felson & Tedeschi, 1993, p. 307), threats to this identity may be especially prone to violence.

The social interactionist theory was developed by criminologists and incorporates social-psychological theory, such as resource theory (Felson & Tedeschi, 1993). This theory “requires an understanding of the phenomenology of actors, who may view their own harm-doing as legitimate and even moralistic” (p. 296). Thus, the perceptions, judgments, expectations, and values of individuals engaging in violence must be understood to understand why they use violence. Despite its development independently from patriarchy, the social interactionist theory helps to understand how a firmly entrenched gender identity based in patriarchy, when threatened, may illicit feelings of justified violence toward the individual deemed to be a threat.

This theory also rings similar to feminist scholars such as Hunnicutt (2009) and Anderson (1997, 2005) who call for an understanding of the context in which an individual uses violence. Anderson (2005) notes that feminists have tried to redefine domestic violence as a pattern of coercive control (part of the definition of violence used by Felson and Tedeschi). While the social interactionist theory has been used in some cross-cultural studies, it has not, to date, been used extensively to explain violence against women.

Theories incorporating threats to traditional gender identity are especially useful for explaining family violence in societies in which men's traditional power in the family has eroded while women's power has increased (i.e., as women increase participation in the work force). This connection will be described in more detail under Status Inconsistency and Social Change theories, below.

Conflict as a Source of Violence

A non-gendered approach to violence, *conflict theory* assumes that people are constantly struggling for status in society, with the goal of dominance and power. Male and female relationships are no exception, and therefore violence between partners occurs. Conflict is not, in and of itself, viewed as problematic unless it is unresolved; conflict may in fact bring about desired change (Sprey, 1969). This theory has been used to explain general patterns of violence in society and the dominance hierarchies that result. Hunnicutt (2009) criticizes this theory for being too simplistic to explain violence against women in full, but recognizes the theory for its contribution to understanding the stratification of society, and why dominance hierarchies contribute to violence.

Access to Resources

To explain why some men in patriarchal societies do not use violence, scholars from varying disciplines have posited that men who benefit most from patriarchy (i.e., those who have the most power through financial and social resources) do not need to use violence unless the system is threatened. Men with the least power in patriarchal systems (e.g., those with lower economic status, less education, or unemployed) are more likely to be violent in an attempt to gain power and assert their masculinity (Hunnicut, 2009). Resource theory (a non-gendered theory) asserts that decision-making power in family relationships depends largely on the value of the resources (material or organizational) each person brings to the relationship. Goode (1971) suggested that the more external resources one controls, the less likely one will need to use violence or force to maintain control. Thus, when male members of the household exercise more control and power over resources, those with limited resources may use more violence to regain control. Studies of domestic violence in the US support this assertion, illustrating that domestic violence rates increase as household income decreases (Benson, Fox, & National Institute of Justice (U.S.), 2004; Greenfeld et al., 1998). Feminist scholar Anderson (1997) also cited studies showing that younger men with fewer resources (less education, lower income) are more likely to use violence against their female partners (K. L. Anderson, 1997). In this case, social class helps to determine the resources available to men for the “construction of masculinity”. Anderson incorporated resource theory as one component of a broader feminist theory described earlier in this paper. Together, these perspectives illustrate that, though power may be in the hands of male members of society, that there

are variations in the benefits of male dominated societies, depending on individual men's status within society.

Hunnicutt also ties capitalism with patriarchy, calling the pairing "mutually reinforcing systems of domination" (p. 560) that support men's "breadwinner status." Men who are unable to fulfill this role (i.e., their gender identity) and the social pressure they feel as a result may increase violence against their partners as suggested previously. Furthermore, unemployed men with employed wives are the most likely to use violence against their wives, according to some studies (Gartner & McCarthy, 1991 cited in Hunnicutt, 2009). Theories making a primary link between resources and violence, however, do not explain gender differences in the use of violence seen in different cultures under similar low-resource/low-power circumstances. Low resources as a single factor for violence against women, therefore, only appear to provide a partial explanation for this violence.

Status Inconsistency and Social Change

The phenomenon of social change itself may play a role in violence. *Status inconsistency theory* suggests that violence is more likely to occur when an individual's power or status is inconsistent (high in one setting, low in another), or when norms governing status in the family are ambiguous or changing (e.g., when there is a great degree of social change) (Gelles, 1972). These inconsistencies lead to stress and frustration that may cause wife beating or child abuse. Researcher Yllö found a curvilinear relationship between wife beating and female status, suggesting that changing social norms result in men using violence as a temporary reaction to their loss of power (Yllö, 1983). Hunnicutt (2009) cites studies showing that as societies experience rapid changes in women's roles (such as women entering the work place) violence temporarily increases against women as a

backlash. Atkinson also demonstrated this point by showing that women who earned the greater share of the couple's income were at increased risk for intimate partner violence, but only among men with traditional gender ideologies (Atkinson, Greenstein, & Lang, 2005). Again, the role of traditional gender ideology as a trigger for violence appears in relation to other explanations for violence.

Hunnicuttt notes (2009) that as societies change and advances in gender equality occur (e.g., measured by percent of women in the workplace), patriarchy may still have a great deal of influence on everyday happenings (e.g., masculine behaviors required in the workplace in order to advance). As a result, generally accepted measures of gender equality/inequality may mask the realities of women in terms of domestic violence, especially in times of rapid social change.

Social Acceptance and Transmission of Violence

Scholars from many fields (e.g., social psychology, sociology) proposed theory on the influences of society and family on the transmission of violent behaviors. The social learning theory, a social psychology theory developed in the 1970s by Albert Bandura (Albert Bandura, 1973) is considered one of the most widely used theories to explain violence against women (Jasinski, 2001). From this perspective, aggression and violence are learned and reinforced in a social context, rather than being an innate internal process. A criticism of social learning theory is that it “ignores the social context of aggressive behavior and has little to say about the situational factors that lead to aggression or about the incentives or motivations for aggression” (Felson and Tedeschi, 1993, p. 297). Additionally, Strauss (Murray A. Straus, 1999) critiqued this theory for

not explaining why the majority of individuals exposed to violence within their families do not go on to use violence as adults.

Social learning theory applied to violence is frequently called the intergenerational transmission of violence theory (Jasinski, 2001). Straus (1979), a prominent family violence researcher, identified the family as the place where violence as an accepted behavior is learned and passed on to future generations, and described a power theory, where violence to address family conflicts is believed to be learned in childhood by either witnessing or experiencing physical abuse (Murray Arnold Straus & others, 1976). More generally, Levinson's (1989) multi-cultural comparison of factors contributing to violence against women concluded that "wife beating" occurs more frequently in cultures where interpersonal conflict is typically resolved using violent means.

Riggs and O'Leary (1989, 1996) expanded on the social learning theory to explain courtship aggression. The theory identifies *background* factors (a history of witnessing or experiencing abuse, aggressive personality characteristics, arousability, prior use of aggression, psychopathology, and social acceptance of aggression as a means to resolve conflict) and *situational* factors (interpersonal conflict, substance use, relationship satisfaction, intimacy levels, problem-solving skills, personal expectations of outcomes to violence, and communication style) to predict the onset of violent behavior. This background/situational model was able to account for 60% of the variance in male-to-female episodes of violence during courtship (Riggs & O'Leary, 1996, 1989). Support for the social learning theory has also been found in lesser-developed countries such as Egypt (Yount & Li, 2010).

General Systems Theory/Exchange/Social Control Theory of Family Violence

Exchange/social control theory was used by sociologist Gelles (1983) to explain violence within the family, stating that family members will use violence to achieve their means so long as the costs are less than the rewards gained by doing so. Essentially, Gelles believes that individuals abuse other family members “because they can” (p. 157). Specific elements of the family reduce costs of violence, including the private nature of the family (in Western cultures), inequality in family relationships (male/female, adult/child), and societal/cultural expectations for displays of masculinity (Gelles 1983).

In the early 1970s, Murray Straus originated the general systems theory to explain why violence occurs between family members (Straus 1973). According to this theory, family violence is the product of a positive feedback social system operating at the individual, family, and societal levels. This model attempted to link resource theory, intergenerational transmission of violence, and culture of violence theories (see below), as well as incorporate other risk factors. In 1979, together with Richard Gelles, Straus merged his general systems theory with exchange theory and social control theory, to explain violence that happens within the family (including violence between spouses, child abuse, and other forms of abuse within the family). This theory was called the family violence theory (Gelles & Straus, 1979a). This theory asserts that the origin of violence is within the family and that families perpetuate violence using corporal punishment and other uses of violence to solve family conflict. Straus and Gelles contend that being a part of a family is not completely voluntary, and that conflict resolution of some sort is necessary to relieve tension (Gelles & Straus, 1979b).

In a cross-cultural study of violence, Levinson found support for these theories, showing that norms that lower penalties for using violence in the family include weak or non-enforced laws about wife abuse, lack of support for victims, isolated family living arrangements, positive cultural attitudes toward male aggressiveness, and sexual inequality (Levinson, 1989).

(Sub) Culture of Violence Theory

Like the social learning theory, this theory asserts that individuals learn aggressive behavior through social interactions. This theory expands the social learning theory by identifying why some groups may differ in their acceptance of violence. The theory suggests that some subcultural groups in large, pluralistic societies develop norms and values that emphasize the use of physical violence to a greater extent than is deemed appropriate by the dominant culture (Wolfgang, Ferracuti, & Mannheim, 1967). Wife abuse, therefore, may be more appropriate or desirable by certain groups than others. This theory also explains differences between societies, asserting that family violence will occur more often in societies that are more violent.

Cultural acceptance of violence is enacted through avenues such as violent movies and use of corporal punishment, which may spillover into violence against women (Jasinski, 2001). This theory, however, does not explain why some men within cultures do not use violence, despite exposure to the same messages.

Maximizing Reproductive Potential

Evolutionary theory is primarily responsible for the explanation of violence as a way for men to maximize their reproductive potential, particularly men who are less successful in finding a mate (Jasinski, 2001). Research in support of evolutionary theory

has also shown that men are more likely to use violence against women when a situation that may affect paternity exists (Burch & Gallup Jr, 2004). “Paternal uncertainty”, in which men question whether their children are actually their own, may explain why some women may experience increased abuse, particularly during pregnancy. This theory has been used to explain why Indian women who worked away from home were more frequently abused than women who did not work away from home (Eswaran & Malhotra, 2011).

Evolutionary theory takes into account the long history of human aggression that cannot be explained by exposure to environmental factors such as the media (Buss & Shackelford, 1997). Evolutionary theory also suggests that individuals use aggression to negotiate power and gain resources from others (Buss and Shackelford, 1997). Power and resources are the topics of several theories presented in this paper. Evolutionary theory, however, has not been used to explain violence as extensively as other theories included in this review. While it has clearly influenced the development of other theories of human behavior and aggression, it is limited in its ability to account for social influences or to identify when violence may be more likely to occur.

Discussion

Review of constructs and their related theories illustrates that even the more widely accepted explanations of violence against women in international settings (e.g., Heise’s ecological model) are criticized as inadequate to explain variations in violence observed globally. Existing constructs and theories, therefore, may be considered just a guide to exploring conditions within particular settings; there continues to be a need for

models that illuminate why specific instances of violence against women occur (Bates et al., 2004; Bell & Naugle, 2008).

There are, however, a number of constructs that help explain violence reported by women experiencing breast cancer in Bangladesh, and thus guide a closer examination of the issue in this dissertation. These constructs must be considered for their application to the broader conditions of men and women in Bangladesh, but more importantly, and of relevance to this dissertation, for their application specifically to women with breast cancer.

First, as noted in Chapter 4, Bangladesh is a lower-middle income, male-dominated country with firmly entrenched gender roles. The findings in this chapter would suggest that not only male dominance, but also other hierarchies of domination such as economic status and education, would influence a man's use of violence against a woman and a woman's susceptibility to violence in her home. The relative status of the population under study, by nature of their rural, underserved status, suggests that women experience a higher overall level of violence than women in higher income countries do, and potentially than higher income and education populations in Bangladesh do. In the case of women with breast cancer, particularly those whose treatment may threaten or actually strain already scarce resources, breast cancer could thus be a trigger for increased violence.

In terms of a threat to traditional gender identity, breast cancer may also make it difficult for both men and women to continue their gender roles. Men may find they are unable to provide the economic resources required for treatment, or even to be a father or husband if his wife is gravely ill. This threat to traditional gender identity may be

sufficient cause for violence against a woman with breast cancer, particularly if individuals believe it is “legitimate” and “moralistic” as suggested by the social interactionist perspective. Women in Bangladesh, however, would not behave in a similar way, despite threats to their traditional gender roles, because female gender roles discourage the use of violence.

Social acceptance of violence may be an influence on women with breast cancer if the disease itself is stigmatized, which could further legitimize the use of violence against a woman who has been “devalued” because of her disease. As a country that already has lax laws protecting women from violence, it could be predicted that laws would be less likely to be enforced (and thus more violence to be enacted) for a stigmatized group of women in Bangladesh.

It should be noted that these conclusions are drawn from research defining violence strictly as *physical* violence, and frequently among Western populations. Identifying processes that contribute to broader definitions of violence, such as that developed by the United Nations (UN General Assembly, 1993), and processes specific to unique populations, requires additional research.

It is from this launching point that a further exploration of the impact of breast cancer on Bangladeshi women and their families, feared and experienced violence in relation to breast cancer (including physical and emotional violence and neglect within the family), and the barriers and facilitators of care is proposed. The rationale behind the study questions presented in Chapter 6 is rooted in an appreciation of the unique qualities of Bangladeshi culture, an understanding of barriers to care among South Asian populations and specifically Bangladeshi populations, and potential theoretical

explanations for the violence some women appeared to experience because of serious breast problems.

CHAPTER 6

RESEARCH QUESTIONS AND STUDY METHODS

The goal of this study is to explore, through structured interviews and qualitative interview techniques, the ways in which a potential diagnosis of breast cancer impacts rural Bangladeshi families, and what impacts women's decisions to seek diagnosis, treatment, and follow-up. This study takes an exploratory approach to capture the perspectives of lesser-studied populations in rural Bangladesh, including those of men, and women with breast problems who are not seeking care. Results may inform the development of breast care programs and new research questions in Bangladesh, and add to the sparse literature on barriers to breast cancer care among a native, rural population in South Asia. For the purposes of discussion, "breast problem" is the term I have chosen to describe women with symptoms of breast cancer, but for whom a doctor has not confirmed the diagnosis.

Specific research questions include:

- 1) How do breast problems impact the lives of women and their families in rural Bangladesh?
- 2) What are barriers to and facilitators of decisions to seek diagnosis and treatment for breast problems in rural Bangladesh?

Sampling

The small expected sample size (low incidence of breast cancer in Bangladesh) and sensitive nature of this study lend themselves to a purposive sample of women and men intersecting with the health system for care, with the additional use of respondent-

driven sampling to reach women not actively seeking care for breast problems. Prior efforts to identify breast cancer patients in Bangladesh revealed that many women never seek care for breast problems, or only seek care from alternative medical providers, such as homeopathic or ayurvedic doctors (Story et al., 2012). As a result, it was felt that women with breast problems that were not actively seeking care were an important group to study, in addition to individuals intersecting with the health system. The sample was limited to women from the Khulna Division and, in the case of individuals actively seeking care, drawn from a breast care center based in Khulna City (<http://agbreastcare.org/>). To explore the study questions, interviews were sought from multiple perspectives:

- 1) women who came to the breast care center for an exam and were subsequently referred for a biopsy due to the suspicious nature of their breast problems (n=20).

- 2) husbands accompanying their wives to the breast care center for an exam, and whose wives were subsequently referred for a biopsy due to the suspicious nature of their breast problems (n=20). These husbands were not required to be the husbands of the women described above, and in most cases, they were not.

- 3) women who had not sought an allopathic diagnosis (minimally, in the form of a clinical breast exam) or treatment for their breast problems (n=20).

The study team recruited men and women seeking care from the breast care center and women who were not seeking care via respondent-driven sampling and key informants. All study participants completed a baseline interview and an additional interview three months later. Interviewers asked participants if they knew of anyone with breast problems who has not come for care, and if so, asked if they would be willing to

share information about our study with that person in an effort to recruit women with breast problems who were not seeking care for an interview. Additionally, leaders from the local medical community assisted in recruiting women to the study via word of mouth and provided phone numbers to women to reach our study interviewers.

The survey consisted of structured interview questions with closed- and open-ended answers and an audio-recorded interview of open-ended questions. The baseline interview captured sociodemographic information, breast symptoms and duration, measures of the level of physical and sexual abuse, and open-ended questions to elicit the impact of breast cancer on women and the family, and their experience of barriers and facilitators to care. The three-month follow-up was used to review decisions about their diagnosis and care, assess additional impacts on the family, discuss barriers and facilitators to care, including that of violence, and to identify facilitators among women who obtained a recommended biopsy. Interview questionnaires are provided in Appendix C.

Inclusion Criteria

All participants were required to be between 18 and 85 years of age and healthy enough to sit through a 45-minute interview. Women who were recommended for a breast biopsy, and women experiencing breast problems but not seeking care must have had breast problems (defined as a lump, ulceration, nipple inversion, discharge, mass, pain or other breast problem that had been present for 2 or more months or which had become worse over time) to be eligible for the study.

Exclusion Criteria

Women under 18 or over 85 years of age; women who were too ill to comfortably sit through a 45-minute interview; and women with breast problems previously diagnosed

as non-cancerous, as judged by a physician (e.g., fibroadenomas or fibrocystic breasts) were not included in this study.

Human Subjects Ethical Approval

The Arizona State University (ASU) Office of Research Integrity and Assurance approved this study prior to implementation in the field (Appendix E). In addition to approval of the study by ASU, the study also received approval from the NGO Affairs Bureau in Bangladesh.

Training

The lead investigator trained research staff in ethics related to human subjects and on dealing with women who may be victims of violence. The World Health Organization brochure on spousal abuse victims in research was used as a resource (“WHO | Putting women first,” n.d.). Staff were also trained in counseling patients facing a cancer diagnosis.

Informed Consent

Interviewers read study participants information about the study and gave participants the opportunity to ask questions prior to beginning the interview. Oral consent was obtained from all participants. Each participant was given his/her own copy of the information sheet to take home unless he/she specifically requested not to receive a copy. A copy of the information sheet is provided in Appendix F.

Interviewers offered all women information on how and where to seek help if they were experiencing problems related to their breast problem, including violence. A non-governmental organization with a long history of dealing with violence against women (among other social issues) was available as a resource for dealing with critical cases (<http://banchteshekha.com/>).

Follow-Up Procedures

The interviewers collected information from study participants to schedule follow-up interviews (Appendix G). The study team kept this information in a double-password protected computer file.

An overview of study participants, measurement tools, sampling and recruitment efforts, and times in which information was collected is provided in Table 6.

Table 6: Study Overview

Participants	Measurement Tool	Sampling/Recruitment	Measurement Period
Women recommended for breast biopsy (n=20)	Tablet-based interview	All women receiving a recommendation for biopsy from the breast care center	Baseline and 3-month follow-up interview
Husbands of women recommended for biopsy (n=20)	Tablet-based interview	The husband of women receiving a recommendation for biopsy from the breast care center	Baseline and 3-month follow-up interview
Women not seeking care for breast problems (n=24)	Tablet-based interview	Respondent-driven sampling from key informants and patient participants	Baseline and 3-month follow-up interview

The Interview Team

The interview team consisted of two men and two women who resided in the Khulna Division of Bangladesh and were native Bengali speakers. One additional team member provided oversight of the interviewers and provided regular feedback to the study author regarding interview progress and issues in need of clarification. Interviewer training was held from January 10-12, 2013 in Khulna city. This three-day training was designed to build competency among the interviewers for accurate and effective data collection in the field using the prescribed study instruments and tools. The training

covered study objectives and methods, human subjects' protection, an overview of breast cancer, interacting with victims of domestic violence, interviewing techniques, and review and practice using the interview protocol and electronic tablet provided for data collection (including audio recordings). Interviewers practiced interviewing through role-play during the three-day training and then practiced for a two-week period with their peers prior to the first interview in the field. The lead investigator addressed questions about the interview protocol and technical difficulties encountered with the data collection tools at that time and as needed throughout study implementation.

Data Analysis

Data analysis consisted of the following elements: 1) Descriptive information from the structured, closed-ended interview about participant socio-demographic characteristics, women's empowerment, and experience of abuse, and 2) A qualitative analysis of structured, open-ended audio-recorded interviews to answer the proposed research questions.

Data Preparation

An independently contracted company first transcribed and then translated to English the Bengali audio-recorded interviews. Translated interviews were then analyzed for themes of relevance to this study, drawing from topics suggested as theoretically important, a review of the literature on barriers, and through review of interviews for themes related to the study questions but not previously identified in the literature.

Codes were initially developed from the literature review on barriers, with additional codes added after review and discussion of completed interviews by a coding team. A codebook was then created to define how codes were to be identified in the

interviews. Inclusion and exclusion criteria, as well as typical and atypical exemplars, were noted for each code in the codebook. Overall, 16 codes were finalized for coding in the interviews (Table 8).

The coding team consisted of three individuals: the study author (female), and two research assistants, one with ties to the Bangladesh community, both female. All team members practiced and final coded the same set of interviews, modeled after the findings of Hruschka, et al. (2004). The unit of analysis for coding consisted of a segment, which consisted of a question by an interviewer, followed by a response from the respondent. The team went through six rounds of practice coding, consisting of 493 total unique segments, or 21% of all interview segments ($n=2343$ total segments, or an average of 19 segments per interview), to identify codes in need of further clarification and obtain uniform interpretation and application of the codes across different coders. Practice coding rounds consisted of between one and six interviews, or 20 and 168 segments. Table 7 provides an overview of the process involved in building interrater reliability.

The lead investigator assessed interrater reliability for each code using Krippendorff's alpha. Krippendorff's alpha was chosen because it allows for assessment of the reliability of more than two coders at a time, and for its utility as an intermediary diagnostic tool as well as a final determinate of the overall reliability of the coding schema (Hayes & Krippendorff, 2007). Krippendorff notes that the degree of reliability deemed acceptable depends on the costs of drawing invalid conclusions from the data, but has suggested a minimally acceptable alpha of .667 (Krippendorff, 2004). For the purposes of this study, Krippendorff's alphas of .70 or higher were considered sufficient;

an alpha lower than .70 was an indication that further refinement of the codebook and the team's understanding of the code was required. The lead investigator provided feedback to the team in the form of conversations and documentation of the discrepancies in codes (in both narrative form and actual Krippendorff's alphas). Ultimately, the study author made the final decision on reported codes. The codebook was updated after each practice round and finalized prior to final coding of all interviews. Interviews and their final codes were entered into the software package MAXQDA 12 (Release 12.0.2) for analysis. The final codebook is provided in Appendix G.

Table 7: Rounds and Segments Coded Prior to Final Coding

Prior to final coding, three coders coded and discussed the following rounds:
Round 1: 10 random segments from different interviews
Round 2: 112 segments
Round 3: 80 segments
Round 4: 123 segments
Round 4.5: 123 segments (Repeat of Round 4)
Round 5: 168 segments
Round 6: 123 segments
493 total unique segments, or 21% of all segments (n=2343 total segments)
Mean segments per interview = 19.2

Krippendorff's alphas were calculated for each code once coding was completed for all interviews. Results by code, as well as the total number of segments containing a specific code, and the total number of participants reporting each code are provided in Table 8. The Krippendorff's alphas suggest that there was generally a good level of agreement or better on most codes with the exception of religion. Less than ten segments were coded for religion, and ultimately no interview segments contained this code, which is responsible for the low reliability estimate.

Table 8: Inter-rater Reliability and Frequency of Codes by Segment and Participant Reports

Code	Krippendorff's α	Total Segments Containing Code n (%)	Participants Reporting n (%)
Role Impact	.78	27 (1.2)	18 (28.6)
Family Impact	.79	163 (7.0)	45 (71.4)
Fear of Treatment	.93	53 (2.3)	29 (46.0)
Fatalism	.82	31 (1.3)	17 (27.0)
Health System Interaction	.73	47 (2.0)	23 (36.5)
Modesty	.97	26 (1.1)	16 (25.4)
Lack of Knowledge	.84	98 (4.2)	50 (79.4)
Alternative Medicine	.92	99 (4.2)	34 (54.0)
Religion	.37	0	0
Stigma	.86	39 (1.7)	16 (25.4)
Access	.83	66 (2.8)	30 (47.6)
Inability to Pay	.91	165 (7.0)	44 (69.8)
Economic Control	.91	14 (1.0)	5 (7.9)
Other	.76	29 (1.2)	15 (11.1)
Physical/Sexual/Emotional Abuse	.75	48 (2.0)	18 (28.6)
Facilitator	.81	212 (9.0)	56 (88.9)

Final codes for all surveys were entered into the qualitative data analysis software MAXQDA to provide summaries of codes by interview and allow for additional qualitative data analysis.

Survey data (non-audio recorded) were entered into The Statistical Package for the Social Sciences, Version 23 (SPSS, Version 23.0) and cleaned prior to descriptive reporting. SPSS was also used to examine differences in study groups on limited factors.

Descriptive Data Analysis

Structured, close-ended survey data provided general characteristics of the study population. Descriptive information includes age, marital status, education, religion, economic status, women's empowerment, and experience of violence. This information mirrors questions from the 2007 Demographic and Health Survey for Bangladesh (hereafter, the "2007 Bangladesh DHS"). The 2007 Bangladesh DHS provides a reference

to population-based information for identical or nearly identical survey question responses.

I also report survey results for key decisions related to diagnosis: (1) how long women had had a breast problem before seeking care from an allopathic doctor and (2) how many women recommended for a biopsy actually received one.

Research Question Analysis

To explore research questions, a qualitative analysis of interviews using coded interview data was completed. In instances where examples of codes are illustrated through quotes, quotes were selected based on how clearly and concisely they represented the set of texts included in that code. As recommended by Ryan (1999) I gave greater weight to quotes from segments that all three coders had agreed on. However, I also included some quotations that were coded by only one or two coders if they reflected an important atypical example of the code. A description of the analysis process by research question follows.

The first overarching research question, reported in Chapter 8, is *how do breast problems impact the lives of women and their families in rural Bangladesh?* To answer this research question, all interviews were coded for descriptions of the negative impact of breast problems on the family. Furthermore, instances of negative impacts were specifically elicited for physical or emotional abuse (including neglect) of a woman with breast problems (independent of or indirectly related to breast problems).

The number of study participants who reported negative family impacts (including the categories of negative family impacts identified) and physical or emotional abuse, as well as examples of these codes through direct quotes are provided.

Negative impacts are distinct from barriers to breast problem care seeking, diagnosis, and treatment described in Chapter 9 in that they describe the difficulties families face when dealing with breast problems, but do not necessarily result in a delay or barrier to care. These negative impacts may be important for understanding the context in which women deal with their breast problems, particularly as programs are being developed to assist women with breast problems in obtaining care, but may be independent of actual barriers.

The second overarching research question, reported in Chapter 9, is *what are the barriers to and facilitators of decisions to seek diagnoses and treatment for breast problems in rural Bangladesh?*

To answer this question, interview data was coded and analyzed to identify themes relevant to the barriers and facilitators separately. Barriers identified in the literature for South Asia provided a basis for coding barriers. Although a range of literature on barriers to care in South Asia exists (as illustrated in Chapter 2), very little information about barriers to care among native residents and particularly among rural populations has been studied, and no known literature incorporates input from men or women with breast problems who are not engaged in care seeking. For this reason, it was felt that literature-derived barriers were an important starting point for exploring barriers in rural Bangladesh.

After identifying commonly reported barriers derived from the literature, I grouped them into categories related to the health system, economic barriers, attitudes, beliefs and norms, lack of knowledge, religion, and an “other” barrier category to capture barriers named by interview respondents, but that did not fit into the major codes. The

number and percent of barriers within each are reported, by men and women and overall. Direct quotes illustrating barriers are provided.

Similarly, facilitators were grouped by categories identified in the process of coding interviews and reported for all study participants who received a biopsy by the three-month follow-up interview. The number and percent of facilitators for each category are reported, by men and women and overall. Direct quotes illustrating facilitators are provided.

Limitations

The small sample size of this study and qualitative nature of the design create limitations for this study in a few important ways. First, despite the inclusion of three distinct study groups, two time periods for interview administration, and the rural nature of this study population, the small sample size of this study means that no definitive conclusions can be drawn about differences between study groups, between the study population and larger populations in Bangladesh, or about differences in reporting between interview time periods. In some cases, comparative data and statistical associations are provided from which tentative conclusions may be formed or further hypotheses may be developed, but attempts to draw clear distinctions are not and cannot be concluded.

Another limitation of this study is that the limited time period of study and the nature of the study populations do not allow for the study of actual disease status (breast cancer or not) and severity of disease (stage of breast cancer), nor does it track the outcomes of women with breast cancer in terms of survival.

Finally, interviews with study participants were conducted by native Bangladeshis and transcribed and then translated into English. Although this was advantageous in terms of accessing communities, it also potentially led to some implicit understandings of meaning during the interviews that are not clear to the non-native Bangladeshi. While every effort was made to clarify instances of obscured meaning, it is possible that some coding distinctions were not identified as a result.

Despite these limitations, this study helps to understand a population that is generally not studied, that of native, rural South Asian women and men, and particularly a group that is not typically accessible, that of women not seeking care for a breast problem. The majority of literature on barriers to breast cancer care among South Asian women relies on immigrant populations interacting with the health system or not currently experiencing illness, and only incorporates the perspectives of women. Furthermore, the limited number of studies conducted in South Asia often utilize university or urban populations that are more educated and have higher incomes than the population at large. The exploratory nature of this study is thus warranted and represents an initial effort to understand the circumstances of and identify important factors for future consideration for rural men and women dealing with breast problems in Bangladesh.

CHAPTER 7

THE STUDY POPULATION

Abstract

This chapter provides an overview of study participant socio-demographic characteristics, overall wealth, women's empowerment, and experience of or enactment of violence. This chapter also provides similar data from the 2007 Bangladesh Demographic and Health Survey results for Khulna Division residents and thus suggests the degree to which study findings may apply to other women and families experiencing a breast problem in the Khulna Division. Study participants consisted of 43 women (19 women recommended for biopsy at a breast care clinic and 24 women with breast problems not seeking allopathic care), and 20 husbands of women recommended for biopsy at a breast care clinic, for a total of 63 study participants.

Results suggest that study findings should be applied cautiously, and that study participants may be more educated and have more conservative views towards women's empowerment than 2007 Khulna DHS respondents. Explanations for these findings are unclear but provide additional context for the following chapters.

Background Characteristics

Overall, 43 women (19 women recommended for biopsy at a breast care clinic, 24 women not seeking allopathic care), and 20 husbands of women seeking care at a breast care clinic and also recommended for biopsy were interviewed from the Khulna Division.

To provide perspective on the similarity of the study groups to representative samples of Khulna men and women, results for background characteristics, overall wealth, women's empowerment and experience of or enactment of violence of study respondents in comparison to the 2007 Demographic and Health Survey for the Khulna Division (hereafter referred to as the 2007 Khulna DHS) are provided, below (Demographic, 2009) . The study questionnaire in most cases (exceptions will be noted) used the same questions used by the 2007 Khulna DHS to allow for this examination.

Women respondents are shown in comparison to the 2007 Bangladesh DHS Individual Recode set for ever-married women aged 15-49 years (n=1711). Husbands of women recommended for biopsy were compared to the 2007 Male Recode set for ever-married men aged 16-54 (n=624). Household wealth indicators for both groups were compared to the 2007 household recode set for wealth indicators (n=2223). A further breakdown of study group findings and how they compare to the Khulna Division is provided in supplemental tables 26-28 in Appendix G.

Age, Marital Status, Religion

Age is provided for both samples as a point of comparison, although no attempt was made to match samples based on age. The 2007 Khulna DHS data set for ever-married women aged 15-49 was chosen as a comparison because it was similar in age range and provided a basis for examining the samples together for other equivalent measures.

Table 9: Female Study Participants versus 2007 Khulna DHS for Age, Husband's Age, Marital Status, Religion, and Education

	Female Study Participants n=43	2007 Khulna DHS (Ever-married women aged 15-49 years) n=1711
Age: Mean (Range)	34.7 (18,60)*	30.9 (15,49)*
Husband's Age: Mean (Range)	46.0 (21,90)*	39.6 (17,91)
Marital Status: n (%)		
Currently Married	34 (81.3)	1564 (91.4)
Separated	4 (9.3)	26 (1.5)
Deserted	0	20 (1.2)
Divorced	1 (2.3)	34 (2.0)
Widowed	3 (7.0)	67 (3.9)
Never Married	1 (2.3)	0
Religion: n (%)		
Islam	41 (95.3)	1565 (91.5)
Hinduism	2 (4.7)	146 (8.5)
Buddhist	0	0
Christian	0	0
Other	0	0
School or Madrasha: n (%)		
None	10 (23.3)	482 (28.2)
School	32 (74.4)	1207 (70.5)
Madrasha	1 (2.3)	19 (1.1)
Both	0	3 (.2)
Highest level of school: n (%)		
None	10 (23.3)	482 (28.2)
Primary (1-5)	8 (18.6)	495 (28.9)
Secondary (6-10)	19 (44.2)	575 (33.6)
College +	6 (14.0)	159 (9.3)
Husband's education level: n (%)*		
None	10 (23.3)	546 (31.9)
Primary (1-5)	8 (18.6)	446 (26.1)
Secondary (6-10)	10 (23.3)	434 (25.4)
College+	14 (32.6)	284 (16.6)

*8 ages missing for female study participants; 11 husband's age missing for female study participants; 1 husband's education level missing for female study participants; 1 missing husband's education level for 2007 Khulna DHS.

Table 9 shows that female study participants represented a wide range of ages (18-60), which is important, given the younger age at diagnosis for breast cancer among South Asian women in comparison to Western populations (Leong et al., 2010; Velikova et al., 2004). The large majority of female study participants were married and of the Islamic religion, which would be expected given that Bangladesh is a largely an Islamic country, and as illustrated in the 2007 Khulna Division sample.

Table 10: Male Study Participants versus 2007 Khulna DHS Ever Married Men Aged 16-54 for Age, Marital Status, Religion, and Education

	Husbands of Women Recommended for Biopsy n=20	2007 Khulna DHS Men (Ever married Men aged 16-54) n=624
Age: Mean (Range)	50.6 (30,72)	37.4 (16,54)
Marital Status: n (%) category)		
Currently Married	20 (100.0)	614 (98.4)
Separated	0	2 (.3)
Divorced	0	4 (.6)
Widowed	0	4 (.6)
Religion: n (%)		
Islam	16 (80.0)	569 (91.2)
Hinduism	4 (20.0)	55 (8.8)
Buddhist	0	0
Christian	0	0
Other	0	0
School or Madrasha: n (%)		
None	2 (10.0)	423 (67.8)
School	17 (85.0)	15 (2.4)
Madrasha	1 (5.0)	10 (1.61)
Both	0	176 (28.2)
Highest level of school: n (%)		
None	2 (10.0)	176 (28.2)
Primary (1-5)	0	197 (31.6)
Secondary (6-10)	10 (50.0)	160 (25.6)
College +	8 (40.0)	91 (14.6)

Men in this study sample (Table 10) on average report older ages than female study participants ($p=.000$). All men were married and the vast majorities were of the Islamic religion as would be expected of this sample. The Hindu religion may be somewhat overrepresented in the study sample, compared to the Khulna Division as a whole.

Education

Almost a quarter of female study participants had no formal schooling, but those who did reported greater percentages of secondary or higher education for themselves and their husbands than would be expected given the 2007 Khulna Division sample. Men also, had rates of secondary education or higher than would be expected given the education of individuals reporting in the 2007 Khulna DHS.

Income and Wealth

Table 11 illustrates the total number of wealth indicators reported by study respondents and 2007 Bangladesh DHS households. Wealth indicators are sixteen household items that are each equally weighted to provide an indication of overall wealth. The sixteen items include electricity, radio, television, mobile telephone, non-mobile telephone, refrigerator, almirah or wardrobe, table, chair, watch, bicycle, motorcycle/motor scooter/tempo, animal-drawn cart, car or truck, motor boat, and rickshaw. Male study participants report a greater number of wealth indicators ($p=.002$), as well as a greater average monthly income ($p=.000$) than female study participants. Female study participants appear closer to Khulna households in terms of overall wealth.

Average monthly household income and perception of wealth in comparison to neighbors was not collected in the 2007 Bangladesh DHS.

Table 11: Household Income and Wealth Indicators; Study Sample Participants versus 2007 Khulna Division DHS Household Sample

	Female Study Participants n=43	Husbands of Women Recommended for Biopsy n=20	2007 Khulna Division Households n=2223
Sum of Wealth Indicators (Max 16): Mean (Range)	5.5 (2,10)	7.5 (3,12)	4.8 (0,12)*
Average monthly household income: Mean (Range)	6837 (2000,20000)	12150 (2000,30000)	NA
“Compared to Neighbors”: n (%)			
Better than neighbors	8 (18.6)	8 (40.0)	NA
Same as neighbors	12 (27.9)	9 (45.0)	
Worse than neighbors	23 (53.5)	3 (15.0)	

*2 sum of wealth indicators missing for 2007 Khulna Division Households

Women’s Empowerment

Table 12 shows that the majority of women in the study sample did not work outside the home for pay in the last 12 months and reported that their husbands made decisions for daily purchases and about their health care for themselves. A similar percentage of women report going for health care independently or with small children versus accompanied by another adult. Women in this study sample report acceptance, on average, of nearly three different types of violence from their husbands. These measures together, as indicators of women’s empowerment, suggest a trend of lower empowerment among study sample women than among women in the 2007 Khulna DHS sample.

Table 12: Women's Empowerment Indicators

	Female Study Participants n=43	2007 Khulna DHS (Married Women aged 15-49 years) n=1711
Work Outside the Home for Pay in Past 12 Months: n (%)		
Yes	9 (20.9)	682 (39.9)
No	36 (83.7)	1029 (60.1)
Decision Making for Daily purchases: n (%)*		
Respondent	8 (18.6)	556 (32.5)
Husband	26 (60.5)	305 (17.8)
Respondent and Husband	2 (4.7)	515 (30.1)
Someone Else	3 (7.0)	176 (10.3)
Respondent and Someone Else	3 (15.0)	159 (9.3)
Decision making for health care for self: n (%)*		
Respondent	11 (26.2)	267 (15.6)
Husband	22 (52.4)	462 (27.0)
Respondent and Husband	4 (9.3)	738 (43.1)
Someone Else	1 (2.4)	116 (6.8)
Respondent and Someone Else	4 (9.5)	128 (7.5)
Goes for health care independently or with small children: n (%)*		
Yes	21 (53.9)	1153 (67.4)
No	18 (46.2)	558 (32.6)
Attitude toward violence (Scale of 0 to 4 where higher is more accepting): Mean (Range)	2.8 (0,4)*	0.6 (0,4)*

*1 decision making for daily purchases missing for female study respondents; 1 decision making for health care for self missing for female study participants; 4 goes for health care independently or with small children missing for female study participants; 5 attitude toward violence missing for female study participants and 12 missing for 2007 Khulna DHS.

Seventy percent of the men in this study sample reported that their wives or that they and their wives jointly made decisions about daily purchases, which appears similar to Khulna Division reports (Table 13). Additionally, both men in this sample and the sample of Khulna Division men reported no or low average levels of acceptance of violence toward women on the four measures noted above.

Table 13: Men's Attitudes toward Decision Making Power and Violence

	Husbands of Women Recommended for Biopsy n=20	DHS 2007 Khulna Division Men (Ever Married Men Aged 16-54) n=624
Decision Making for Daily purchases: n (%)		
Respondent	6 (30.0)	210 (33.7)
Wife	10 (50.0)	41 (6.6)
Respondent and Wife	4 (20.0)	285 (45.7)
Someone Else	0	17 (2.7)
Respondent and Someone Else	0	71 (11.4)
Attitude toward violence (Scale of 0 to 4 where higher is more accepting):		
Mean (Range)	0*	.6 (0,4)

*3 missing attitude toward violence among husbands of women recommended for biopsy

Violence Enacted Against Women

Less than a quarter of female study participants reported physical violence and only one reported any sexual violence (being forced to have sex with her husband against her will) in the three months prior to administration of the survey (Table 14). Study measures of violence were collected for a different duration than 2007 Khulna DHS, but the 2007 Khulna DHS data suggest that physical violence, and to a lesser extent sexual violence, may be a part of many married women's lives.

Table 14: Women's Experience of Violence from Their Husbands

	Female Study Participants n=43	2007 Khulna DHS (Married Women aged 15- 49 years) n=693
Experience of physical violence from husband: n (%)* Yes No	(previous three months) 7 (16.3) 34 (82.9)	(ever) 357 (51.5) 332 (47.9)
Experience of sexual violence from husband: n (%)* Yes No	(previous three months) 1 (2.4) 40 (97.6)	(ever) 116 (16.7) 573 (82.7)

*2 experience of physical violence for female study participants, 4 missing for 2007 Khulna DHS; 2 experience of sexual violence from husband missing for female study participants, 4 missing for 2007 Khulna DHS.

Almost thirty percent of husbands of women recommended for biopsy, despite their lack of acceptance of violence reported above, were found to have ever used physical violence against their wives in the past three months, although none reported sexual violence (Table 15). Over half of all men surveyed in Khulna Division reported ever using physical violence against their wives, and less than five percent reported ever using sexual violence, although almost ten percent of men from this sample did not answer these questions (n=60).

Table 15: Men's Use of Violence against Their Wives

	Husbands of Women Recommended for Biopsy n=20	2007 Khulna DHS Men (Ever married Men aged 16-54) n=624
Physical violence used against wife: n (%) Yes No	(ever) 6 (33.3) 12 (66.7)	(ever) 340 (60.3) 224 (39.7)

Sexual violence used against wife: n (%)	(ever)	(ever)
Yes	0	27 (4.8)
No	18 (100.0)	537 (95.2)

*2 physical violence used against wife missing for husbands of women recommended for biopsy and 60 missing for 2007 Khulna DHS men; 3 sexual violence used against wife missing for husbands of women recommended for biopsy and 60 missing for 2007 Khulna DHS men.

Discussion

Overall, it appears that women and husbands of women recommended for biopsy have relatively high levels of education in comparison to 2007 Khulna DHS women and men. These socio-economic indicators are frequently linked to disparities in health and are thus important potential distinctions for this study.

In terms of women's empowerment and experience of violence, women in the study sample report relatively low levels of empowerment through being less likely to work outside the home (with potentially little control of their own economic resources), having less likelihood of accessing health care independently (meaning, more reliance on others to accompany or allow them to go to an appointment), and what appears to be a high degree of acceptance of violence in their lives. The trend of low empowerment indicators when viewed next to 2007 Khulna DHS data suggests that there may be a real difference in the level of empowerment among study sample women. Follow up on this finding with study personnel led to the suggestion that women with serious illness sometimes become more conservative in their views (and thus more likely to defer to their husband), which may partially explain this finding. This study, however, cannot confirm this explanation.

Regardless, over 50% of married women in the Khulna Division experience some form of physical violence from their husbands in their lifetimes, and over 16% experience sexual violence, suggesting that violence is a relatively common event in the marital household regardless of a breast problem or breast cancer diagnosis.

Male study participants appeared to have less conservative views on women's empowerment than female study participants, which could be a reason they brought their wives for examination in the first place (a reflection on the particular sample of men), the a result of the sensitive nature of the topic, or some other unknown influence. Data collected on violence enacted against their wives appears to reflect lower use of violence, but also suggests, by nature of the percentage reporting, that these men are willing to discuss their own use of violence within the marriage (almost 30% reported enacting some form of violence against their wives in the last three months), contradicting their attitudes toward the acceptability of violence. One potential explanation could be that they find other instances in which violence is justified that are not reflected in the examples provided by the interview questions on acceptability of violence (see Appendix C for interview questions specific to acceptability of violence among husbands of women recommended for biopsy). Khulna Division men also exhibit this trend (low overall acceptance of violence and greater percentage reporting of use of violence, lending weight to the above explanation.

Study sample descriptives, and similarities and dissimilarities between the study sample and general study population provide an important grounding for additional exploration of study findings in Chapters 8 and 9, and issues of potential interest for future studies.

CHAPTER 8

THE IMPACT OF BREAST PROBLEMS ON RURAL BANGLADESHI WOMEN AND THEIR FAMILIES

Abstract

The impacts of women's breast problems on women and their families provides important context for understanding the barriers and facilitators to care explored in Chapter 9. Women's health and prior care seeking, and the negative impacts of breast problems on women and their families are explored.

Negative family impacts fell into four categories: inability to continue gender roles because of illness or efforts to treat breast problems, time- and energy-intensive efforts to raise money for care, emotional impacts such as fear and anger, and a reduction in living standard because of paying for treatment. One additional area, physical and emotional abuse (including neglect) was specifically explored within the family. Little physical abuse was reported, however active and passive emotional abuse were more frequent, including two women who were divorced as a result of their breast problem.

The challenges women and their families experience because of breast problems, particularly in the low-resource setting of rural Bangladesh, would suggest, according to some theories of violence presented in Chapter 3, that women with breast problems may be more vulnerable to various forms of violence. While little physical abuse was reported, emotional abuse appears to be a serious problem with devastating consequences for women in this setting.

Earlier chapters have attempted to describe the socio-cultural influences on individual lives that directly and indirectly affect the health of women with breast problems and their families. This chapter seeks to understand more specifically the illness experience of families dealing with a breast problem. Specifically, the ways in which a breast problem negatively impacts the family, why violence occurs in women's lives, and whether breast problems are a trigger for violence against women are explored. Theories of why violence against women occurs, described in Chapter 3, suggest that threats to gender identity among men in patriarchal societies like Bangladesh could be a cause of violence. Among families dealing with a breast problem or breast cancer in this low

resource setting, the financial strain, threat of breakdown of the family unit, and vast time and emotional resources required to deal with a breast problem are all plausible threats to gender identity that could result in increased violence.

This chapter explores responses from study participants about their experience dealing with a breast problem to identify these types of negative impacts, and provides a context for understanding the barriers and facilitators to breast problem diagnosis, treatment and follow up described in Chapter 9.

Women's Breast Cancer Symptoms

Interviewers asked women in this study (19 women recommended for biopsy and 24 women not seeking allopathic care) to report on their experience of breast cancer symptoms. The most frequently reported symptom was either a persistent lump or a lump that was growing in size (Table 16). Women reported between one and four symptoms overall, with an average of 1.4 symptoms. All women, therefore, had signs that suggested a doctor should examine them. Reports of symptoms by men are not provided, with the belief that their reports may not be as reliable as women's may be.

Table 16: Breast Cancer Symptoms Reported by Women

Symptom	Female Respondent mentions n=43 women*
Persistent lump in breast	16
Lump that is growing in size	27
Swelling or redness of breast	2
Infection of breast	2
Nipple discharge	4
Nipple inversion	2
Peau d'orange	1
Ulceration of breast	1

Other (All “Other” mentions were breast pain)	3
Mean (Range)	1.4 (1,4)

*2 missing

Negative Impacts of Breast Problems on Women and Their Family Members

Negative impacts described by women and husbands of women with breast problems fall into five major groups: negative impacts on gender roles (inability to continue with these roles), “running around” for treatment, including extensive travel, multiple visits to doctors and large amounts of time spent dealing with the health system, emotional impacts such as anger, worry, and fear about the disease and its impact on the family, efforts to raise or borrow money for treatment, and a reduction in standard of living. “Running Around” for treatment and emotional impacts were the most common family impacts (Table 17).

Table 17: Impacts of Breast Problems on the Family

Family Impacts n (%)	Female Study Respondents n=43	Husbands of Women Recommended for Biopsy n=20	All Respondent Mentions n=63
Gender Role Impacts	16 (37.2)	2 (10.0)	18 (28.6)
“Running Around”	15 (34.9)	17 (85.0)	32 (50.8)
Emotional Impacts	13 (30.2)	17 (85.0)	30 (47.6)
Efforts to Raise Money for Treatment	3 (7.0)	4 (20.0)	7 (11.1)
Reduction in Standard of Living	2 (4.7)	0	2 (3.2)

Gender Role Impacts

As noted in Chapter 5, cultural norms in Bangladesh define gender roles rigidly, with women as caretakers of the home and men as the breadwinners. Overall, 18 individuals mentioned role impacts. The most frequently mentioned gender role impact,

mentioned by women, was that of having to cut back on household tasks (n=12). Women mentioned not be able to or allowed to do things like cook, bring water to the home (no faucet exists within most homes in this area), or clean. Women often mentioned in these cases that other family members took on her duties, such as this case of a woman recommended for biopsy:

“Now as I am sick I did not work for last 15 days. I asked one of my daughters to come from her in-law’s house to help me. She has come. I have another daughter who sat for SSC Exam this year. She is also helping me.”

Another woman not seeking care was not able to continue her job after becoming sick, and as a result was not able to earn money for her treatment.

In the most extreme cases mentioned (one woman recommended for biopsy and one woman not seeking care), women were divorced as a result of their breast problem, eliminating their role as a wife completely. This exchange with a woman recommended for biopsy reflects a similar sentiment by the other woman divorced because of her breast problem:

Interviewer: Would you please tell me how your husband behaved with you after you got the chest disease?

Respondent: He did not allow me to take treatment. Now he has got married again and left me. He is living with his new wife in a distant area.

Only two husbands specifically mentioned impacts on their roles, one who had to stop work and incur losses to his business, and another who took on some of the responsibilities of the family. One husband noted:

“Every morning after waking up, I have to do the dishes, bring the water, arrange everything for her cooking, clean the house. I don't get time to cook as by the time I finish doing all this, it turns to be my office time. Even before coming here, I stored a bucket full of water for her so that when she will cook in the evening, she doesn't have to go out of the house.”

“Sometimes my daughter cooks when I can't bear the pain”

--Woman Not Seeking Care

“Running Around”

Over fifty percent of respondents mentioned the great amount of time and other resources required to engage with the healthcare system in a way that was not only affordable, but also deemed to be appropriate for the woman’s care. The term “running around” (বিভিন্ন জায়গায় আমি ছোট্টাছুটি করছি; literally, “I’m running in different places”), was used by many to describe these efforts, including visits to many different doctors (both alternative care/homeopathic and allopathic doctors), travel to multiple providers within the Division, to Dhaka, and in some cases to India, and waiting in different facilities for long periods of time to be seen by a doctor. Some husbands noted that these efforts were especially challenging with a sick patient. One husband mentioned how stressful the process of finding the right place for testing and treatment was, and noted “It’s not all about the money; it needs a lot of hard work. The patient and her family both suffer a lot.”

“We have to run from one place to another. It was a great harassment running here and there with a sick person.”

--Husband of a Woman Recommended for Biopsy

A woman recommended for biopsy noted her difficulties in traveling from place to place, having to find care for her small daughter in the process:

“It would have been best if [the facilities] were in Bagerhat. I had to go to Dhaka first and then Khulna. It’s difficult to have long journeys and finding places to stay. My daughter was very small so I had to take her to my mother in the village.”

Another woman noted that she was not only managing care for her breast problem, but also seeing different doctors for her diabetes, requiring numerous different types of doctors and treatments. This issue of having to deal with other health concerns that interfere with breast cancer diagnosis and treatment is discussed in more detail in Chapter 9.

One woman recommended for biopsy explains her experience, clearly illustrating the many steps women and their families experience as a result of breast problems, and highlighting the additional impact of managing economic resources for care (described in more detail in the next section):

“First I went to our village office, then to Bagerhat clinic...Then they sent me to Dhaka for the Biopsy test...Then I went to Khulna and met a doctor whom I consulted with in our local office. He told me to have an immediate operation in the Islamic Medical College Hospital otherwise...I might die as well. Then I sold all the properties I had and had the operation in Islamic Medical College Hospital. However, the wound where I was operated was not drying up—there is a hole in that place. The doctor said that another operation is necessary to fill the sore in, and he would replace some skin from another part of my body to that place but I did not have enough money so had to refuse that proposal. But after returning home, I had to go to several times to Khulna and two times in Bagerhat for dressing that place [the wound].”

Despite these impacts, one woman recommended for biopsy reported a sense of satisfaction that her efforts have resulted in better care and outcomes:

Interviewer: “Did you face any trouble getting the treatment?”

Respondent: “Not that much because it was helpful for my treatment that I had to move one place to another.”

Efforts to Raise Money for Treatment

Seven individuals (three women and four men) mentioned tedious efforts to locate money to pay for diagnosis and treatment of breast problems. Individuals mentioned

selling land, jewelry, livestock and other personal possessions to raise money for treatment (see quote). Others mentioned knowing someone that could lend them money, or negotiating with doctors for care within the money they could afford to spend.

Among women seeking biopsy who mentioned managing money, efforts to identify ways of lowering costs, such as finding an inexpensive treatment facility and gathering small amounts of money for transport, or raising money or “begging” from the community through schools and other family members were mentioned. These efforts were undertaken while dealing with the stress of a sick patient, or in some cases by the patient themselves.

“One night her [his wife’s] breast started to hurt. It was hurting so much that she started screaming. Our son returned home at around 12 am. The next morning, he said that he’ll take her to hospital. But we didn’t have money. So we were thinking about leasing the little land we have. At last we sold our ox for 13000 Tk. Then our son took us to Khulna. There we got her admitted in a hospital.”

--Husband of a Woman Recommended for Biopsy

Emotional Impacts

Emotional impacts on women and the family were the second-most frequently cited impact among respondents (n=30). Individuals reported emotional responses as a result of fear and anxiety around the disease treatment and outcome, worry about what will happen to the children if the mother doesn’t survive, anger or frustration about having to spend money for treatment or about not having money for treatment, and revulsion about the conditions and circumstances of health care facilities.

All groups as would be expected, expressed emotional reactions about the disease treatment and outcome, but men discussed a greater frequency and variety of emotional

reactions. Both men and women mentioned that it was natural to be upset, and in most cases, this appeared to reflect care and concern for the woman suffering from breast problems, as stated by this husband of a woman recommended for biopsy:

“We were thinking that if it's a normal tumor, then it will be very convenient for us. But if the cells are cancer affected then we have to be more thoughtful. But we were not only anxious. She is one of us and we had to save her by any means, this was the main goal of us.”

Women, both those recommended for biopsy and those not seeking care, mentioned emotional responses from family members when they learned of her disease, including sadness, fear and tension.

“Now also I have lot of tension. I am thinking about the education of my son. How can I give him proper education if I don't live any longer?...I feel weak. I cry and my children cry”

--Woman Recommended for Biopsy

Interviewer: What was your reaction when the doctors suggested a biopsy?

Respondent: Usually everyone becomes very hopeless because of the fact that they are going to die earlier and unnaturally. We became so disappointed that she was going to die so soon...

--Husband of a Woman Recommended for Biopsy

A husband of a woman recommended for biopsy was thinking about the future for his children and expressed concern about how his family would continue if his wife were to die, noting:

“My son is doing an MBA, My daughter is doing a BA (Hons). I was thinking what I would do if something happens to my wife? It will be very difficult to hold the family together.”

Four husbands of women recommended for biopsy as well as two women not seeking treatment mentioned anger about breast problems. All individuals mentioning anger noted men (either themselves or their husbands) being angry about having to spend a lot of money on breast problem diagnosis and treatment, with one exception of a husband who was angry at his wife for not telling him about her problem earlier. Both men and women used the phrase “it is natural” or “it is normal” to describe the angry response.

Interviewer: So, if your husband knows that you are taking treatment for your chest problem what will be his reaction?

Respondent: He will be angry. It is natural because I have been treated by many doctors and a big amount of money has been spent for my treatment and operation. If I again need to go to a doctor now he will be angry. And it is quite natural.

-Woman Not Seeking Care

Reduction in Living Standard

Only two people mentioned a reduction in living standard because of treatment for breast problems, yet the likelihood of this occurrence among poor villagers is high and warrants note. One woman whose doctor recommended her for a biopsy described her circumstances:

“My husband sold everything of my house for arranging money for my treatment. Now I have nothing in my house. He even sold his rickshaw for nine thousand Taka, which he bought through the cooperative society for 18 thousand taka. I have nothing in my house now.”

Another woman recommended for biopsy stated:

“I went to Khulna and met a doctor whom I consulted with in our local office. He told me to have an immediate operation in the Islamic Medical College Hospital otherwise, it has chances of spreading to other parts of my body. Then I told him about my poor financial condition and that I had already spent around twenty thousand for this disease and asked

what I should do. He told me to have [the operation] as soon as possible otherwise I might die as well. Then I sold all the properties I had and had the operation in Islamic Medical College Hospital.”

For families living in already impoverished conditions, these type of impacts can have serious repercussions for the immediate family and potentially future generations.

Physical and Emotional Abuse and Neglect

From the information reported in Chapter 7 we know that in general, the majority of Khulna Division women experience violence within their families at some point in their lives, and that some study respondents report abuse in the last three months. The interviews explored women’s experiences of physical and emotional abuse. Abuse was distinguished as active emotional abuse (insults and negative behaviors) or passive emotional abuse (neglect and indifference) within the context of breast problems. These experiences were defined separately from stigma against women with breast problems, but were deemed important to understanding the context in which women deal with breast problems.

Overall, some form of physical or emotional abuse, including neglect, was reported by almost 40% of female study respondents (n=18, ranging from 26.3 percent of women seeking care to 41.7 percent of women not seeking care) and by three men. The types of abuse described by study respondents are illustrated, below.

Macro-level Abuse

Men reported no direct abuse toward their wives in the open-ended interviews, but one husband of a woman recommended for biopsy provided insight to a macro-level explanation for neglect of women in general, stating:

“Our society is male dominant, and here women are often neglected. It is the same for government and everyone else. This is one of the reasons why the awareness of this kind of disease [breast cancer] is almost non-existent.”

This statement speaks to the general attitude of society toward women as that of neglect or indifference and its relationship to poor awareness of breast cancer, which directly affects the ability of women to acknowledge and seek care for a breast problem. It also points out that neglect of women (as opposed to physical or sexual abuse) has serious ramifications.

Physical Abuse

Two accounts of physical abuse were provided, but both were described as having happened in the past. One woman recommended for biopsy noted that her husband used to beat her severely when she “failed to do something according to his mind.” This woman’s brother also told her that she was responsible for these beatings.

The second woman experiencing physical abuse also reported her husband beating her in the past, and having a mother-in-law who treated her poorly.

Active Emotional Abuse

Thirteen women (30% of all women) and two men noted active emotional abuse in the form of insults and behaviors indicating a negative view toward the women describing them. Women described active emotional abuse primarily from their husbands and in-laws, and sometimes mentioned the need to tolerate the abuse because they are living with these individuals. One woman not seeking care had the following exchange with the interviewer, illustrating this common theme:

Interviewer: So, do you think that if a person gets sick that his/her relationship with others becomes worse.

Respondent: Yes, relationships get worse. Everybody becomes angry. What can I do?

In one case of active emotional abuse of a woman recommended for biopsy, it appears that the breast problem was an excuse used by her mother-in-law for escalating bad behavior related to feelings about the woman's appearance:

Respondent: My mother-in-law is angry about the treatment; she scolds me all the day...She is happy that I have this disease...She is happy that I will die. She is always praying for my death.

Interviewer: Why she is behaving like this with you? You told me that you did a lot for the family.

Respondent: It is because I am dark, not fair.

Her husband also previously physically beat her.

Three women reported anger from family members about having to spend money on a breast problem and about the futility of spending money on her if they expected her to die. In the following exchange, a woman not seeking care for her breast problem as a result of other disease (discussed in more detail in Chapter 9), appears to understand her husband's anger toward her problems:

Interviewer: So, if your husband knows that you are taking treatment for your chest problem what will be his reaction?

Respondent: He will be angry. It is natural because I have been treated by many doctors and a big amount of money has been spent for my treatment and operation [of other diseases]. If I again need to go to a doctor now he will be angry. And it is quite natural.

Another woman described how her family reacted to a doctor's recommendation to receive a biopsy:

"If I ask them to take me to a doctor they become angry. They say, 'You are not going to survive. Then what's the benefit of taking you to doctor?'"

This statement possibly reflects concerns about spending money, but also a relationship with fatalism toward breast cancer, a barrier discussed in more detail in

Chapter 9. The angry nature in which this sentiment is expressed, however, illustrates a form of active emotional abuse.

Interviewer: If a woman near your home gets breast cancer, what will be the attitude of her family towards her?

Respondent: They would not behave well with her I think because this treatment costs a lot of money.

-Woman Not Seeking Care

One husband of a woman recommended for biopsy brought out a theme that this study expected more frequently: that of women being afraid of how their husbands might react if they reveal their problem. He noted that his wife was afraid to tell him about her disease in the initial stages. While women did not explicitly name fear of telling the husband about their disease, the number of cases of reported abuse suggests that this fear might be justified and more widespread than this study identified.

One extreme form of active emotional abuse is abandonment of women through divorce. The two women who were divorced as a result of their breast problem described an inability to find “mental peace” and increased “mental pressure” leading to inability to sleep and feelings of madness. As noted earlier, divorced women, in addition to losing the support of their husband financially and emotionally, also face stigma that can be isolating and detrimental to health.

Passive Emotional Abuse

Ten women (23% of all female study participants) also reported passive emotional abuse in the form of neglect and indifference toward their circumstances by their family members, most frequently their husband and in-laws. All but one of these women were not actively seeking care for their breast problem.

This exchange between the interviewer and a woman not seeking care exemplifies the type of passive emotional abuse experienced by women in this study:

Interviewer: Well, if anyone near your house develops the disease, how do you think their family members will behave with her?

Respondent: They think her a burden. It matters little whether she dies or lives!

Other women mentioned that their husbands, in-laws, and neighbors had little or no concern for the welfare of women with breast problems, or whether women were able to obtain treatment. These types of statements are illustrated in Table 18. The one woman recommended for biopsy who reported passive emotional abuse described her circumstances in the following exchange:

Interviewer: If your husband knows that you are going to get treatment for your breast problem, what will he think?

Respondent: He will not care. My husband does not want my recovery. He is very indifferent to me. He does not have any affection to my son or me.

Interviewer: What is the reaction of the other members of your family? Do they show any concern about this?

Respondent: No, they don't. They don't care if I live or die.

Interviewer: And, about your health? Don't they care?

Respondent: No, they don't care!

Interviewer: What is your feeling of your neighbors about this disease?

Respondent: They feel, 'let her die.' Nobody thinks for others. I went to many for assistance but nobody provided help.

The frequency and intensity of these statements lead to the conclusion that abuse and neglect of women within the household is a relatively common theme in rural Bangladesh, with serious ramifications for care seeking for breast problems.

Table 18: Statements Illustrating Neglect and Indifference toward Female Study Participants

Interviewer: How do your family members treat you? Is there anything negative about their treatment?

Respondent: No, not much. They didn't give much importance to my care. They don't even think of providing me with money for this treatment. They live with their own affairs, not mine.

-Woman Not Seeking Care

Interviewer: What will be the remarks of your parents in law and other members of your family if they know that you are having treatment for your problem?

Respondent: For once they will tell, 'Go and visit the doctor.' They will say it just for the sake of saying. It is just a mouth word but nothing serious. My sickness is not important to them.

-Woman Not Seeking Care

Interviewer: What is the reaction of other members of your family?

Respondent: I haven't told them about this.

Interviewer: What do think? Are they aware of this?

Respondent: No, they have no worries for me. They do not think about me at all.

-Woman Not Seeking Care

Interviewer: Whom did you tell about your problem?

Respondent: I told my husband, mother, and sister-in-law, but they did not take it seriously. They ignored me.

-Woman Not Seeking Care

Interviewer: Have they [her family] expressed any anger that you are going to take some treatment for your disease?

Respondent: No, they do not want to involve themselves into this problem. They do not care for me.

-Woman Not Seeking Care

Discussion

Women in this study report a wide range of symptoms, suggesting that there are study participants with varying degrees of disease, and potentially some women (particularly those not seeking care) who do not have life-threatening disease. All

women, however, by nature of having at least one symptom that has persisted or gotten worse over time, had cause to seek examination by a doctor.

This chapter initially illustrates that breast problems place great strains on family resources, including time, money, and emotional impacts, as well as inhibiting or straining their social roles in the family, particularly among families actively seeking care and among men with traditional gender identities suggested by a patriarchal society. Families also potentially face long-term ramifications for their children's education and financial circumstances as a result, particularly when diagnosis and treatment of a breast problem result in the elimination of family assets.

Descriptive data and narrative reports from women and husbands do suggest that, in particular, emotional abuse occurs relatively frequently, and that breast problems or breast cancer diagnosis exacerbates emotional abuse. Emotional abuse is often overlooked or given little importance in literature on violence against women, but may have a great impact on the lives of women dealing with a breast problem, especially in instances of divorce. Divorced women in Bangladesh face a particular stigma not covered in this study, which leaves them vulnerable and makes it more difficult to obtain care for breast problems.

Theories of violence in Chapter 3 may explain, in part, the types of negative impacts and reports of abuse by women with breast cancer, particularly those that suggest that threatened gender identity may increase violence. One form of abuse noted, however, requires a broader explanation that may be rooted in the value of women in society. The mentions of "they don't care if I live or die" show an indifference toward the woman herself and imply she is easily replaceable, and that this is perhaps preferred to having to

take care of her and spend money on her because of her illness. With typically no resources of their own to draw from, these women have perhaps the most unfortunate circumstances. These attitudes go beyond patriarchy (which has been shown to provide protection for women in some cases), to a view of women as less than human. Furthermore, these attitudes likely apply to women in any circumstance in which breast problems threaten their defined gender role, as they are then no longer of use to the family and potentially a threat to men's gender identities as fathers and husbands. Breast cancer may be just one disease among many in which women face this dehumanizing form of abuse in Bangladesh and perhaps other areas with similar views towards women.

Chapter 9 examines the barriers and facilitators to breast problem diagnosis, treatment, and follow-up in rural Bangladesh, adding another facet to the understanding of the experience of rural Bangladeshi families in dealing with breast problems. Chapter 9 will also consider another potential cause of abuse identified in the literature as barrier to care, that of stigma toward breast cancer. This information should provide insight to the influence of barriers and the role of facilitators, allowing programs to zero-in on strategies to increase care for this vulnerable population.

CHAPTER 9

INFLUENCES ON BREAST CANCER CARE-SEEKING, DIAGNOSIS, AND TREATMENT IN RURAL BANGLADESH

Abstract

This chapter illustrates the barriers to breast problems care seeking, diagnosis, and treatment in rural Bangladesh among study participants, and identifies common themes across barriers. Furthermore, facilitators to receipt of a breast biopsy, an essential tool for accurately diagnosing and treating breast cancer, are identified among women who successfully received a recommended biopsy.

The top five reported barriers were lack of knowledge, inability to pay, inability to access care, fear of treatment, and negative interactions with the health care system. Study participants did not mention stigma as frequently as this study expected, but stigma did exist both as a fear and in the experience of study participants, with some existing stigma posing serious and potentially life threatening effects. Furthermore, women not seeking care were approximately twice as likely to experience some form of physical or emotional abuse as women seeking care were.

Facilitators among women and husbands of women receiving a biopsy fell into five major categories, with the most frequently cited facilitator being support and encouragement from the husband and husband's family. Others included financial arrangements for care, increased knowledge, and awareness, and some individuals reported becoming facilitators of care through their own experience dealing with a breast problem.

Barriers reported largely support the literature and provide a richer understanding of the experience of breast problems in rural Bangladesh. Facilitators, in combination with named barriers, suggest that women's lack of control of resources and attitudes that control her ability to seek needed care proactively work together with the effects of poverty, inadequate health systems, and lack of knowledge that many women and their families experience. Furthermore, the physical and particularly emotional abuse illustrated in Chapter 8 suggests a low value placed on women in general. Together, these contribute to poor quality of life and potentially poor outcomes among this vulnerable group.

Delay of Care and Receipt of Biopsy among Women Referred for Biopsy

Women reported, on average, 38 months since first recognizing a breast symptom at the time of interview, with a range of one to 204 months. Women recommended for

biopsy reported 25 months on average, while women not seeking care reported 49 months on average.

Of 40 study participants recommended for biopsy, 32 (80.0%) received a biopsy. Overall, of the 19 women referred for biopsy, 11 went on to have the biopsy done. Additionally, one woman who was not seeking care at the baseline interview went on to seek care, be referred for a biopsy, and complete the biopsy, for a total of 12 women receiving a biopsy of those (n=22) recommended for a biopsy. All husbands of women recommended for biopsy (n=20) reported that their wives had the biopsy.

Reported Barriers to Care-Seeking, Diagnosis, and Treatment

Identified barriers were grouped into six categories: access to and poor interaction with the health system, inability to pay or lack of control over needed economic resources for care, attitudes, beliefs and norms that affect family's willingness or ability to receive care, lack of knowledge or exclusion from knowledge about breast cancer, other serious disease preventing treatment for breast problems, and an "other" category to capture unique barriers (descriptions of barrier codes are provided in the codebook provided in Appendix E). Reported barriers by number and percent reporting each type are provided in Table 19, as well as the mean and range of unique barriers reported. Supplemental Table 28 in Appendix G provides a further breakdown of barriers by study group.

Table 19: Barriers to Care Seeking, Diagnosis, and Treatment

Barrier Reported: n (%)	Women n=43	Men n=20	OVERALL n=63	Rank
Health System Barriers				
Access	19 (44.2)	11 (55.0)	30 (47.6)	3
Health System Interaction	15 (34.9)	8 (40.0)	23 (36.5)	5
Economic Barriers				
Inability to Pay	29 (67.4)	15 (75.0)	44 (69.8)	2

Economic Control*	5 (11.6)	0	5 (7.9)	10
Attitude, Belief and Norm Barriers				
Fatalism	7 (16.3)	10 (50.0)	17 (27.0)	6
Fear of Treatment	27 (62.8)	2 (10.0)	29 (46.0)	4
Modesty	10 (23.3)	6 (30.0)	16 (25.4)	7
Religion	0	0	0	12
Stigma	5 (11.6)	6 (30.0)	11 (17.5)	8
Women's Travel Outside the Home*	3 (7.0)	0	3 (4.8)	11
Knowledge Barriers				
Exclusion from Knowledge*	1 (2.3)	2 (10.0)	3 (4.8)	11
Lack of Knowledge	33 (76.7)	17 (85.0)	50 (79.4)	1
Other Disease*	7 (16.3)	0	7 (11.1)	9
Other Barrier	5 (11.6)	2 (10.0)	7 (11.1)	9
Unique Barriers Reported: Mean (Range)	4.2 (1,9)	4.0 (0,7)	4.14 (0,9)	

*These barriers were not identified a priori, but were initially identified as an "Other" barrier and felt to be important barriers for independent discussion.

When asked to describe barriers to seeking and receiving care for breast problems (including diagnosis and treatment), the most common barriers reported (either that they had experienced themselves or that they felt other people experienced) were lack of knowledge about breast cancer and its treatment, economic barriers and health system barriers. The use of alternative medicine was a common sub-theme for some barriers and was mentioned by almost 54% of respondents overall. Alternative medicine will be discussed where relevant within the barrier code reports. Barriers to care are described by grouping in the following pages, with sub-themes illustrated through typical and atypical quotes from study participants.

Health System Barriers

Health system barriers included availability of services (Access), and having a poor interaction with the health system once services were identified (Health System Interaction).

Access

Among women and husbands who sought allopathic care, access (defined as difficulty or inability to get to or identify needed care) was a problem for almost 35% of study participants. The most common access problem mentioned was lack of availability of services or cancer specialists (n=19). A husband of a woman recommended for biopsy summarized the situation in this way, illustrating the many ways that lack of availability manifests itself:

“We do not have enough and expert doctors. We should have enough specialist doctors of this disease. We do not have necessary machines. If we have machines then we do not have experts to operate those machines. We do not have enough technicians. While buying these machines we should remember the other things. Because it’s seen that if any x-ray machine of any government hospital gets damaged it takes 2 years to repair. So, these types of problems.”

The next most frequently mentioned access problem was that of distance of the facility from the respondent’s home (n=18). One illustration of this theme is from a women not seeking care who said:

“I think if the medical center was near to my house I could easily go there by myself.”

Another woman not seeking care noted:

“I have to go far from home to visit a doctor and there is no one to look after it in my absence. So, I did not consult a doctor.”

The third most frequently mentioned access problem, was that individuals could not get all aspects of their breast care in one place, and were required to visit multiple doctors, laboratories, and pharmacies in order to get what they needed (n=7). Chapter 8 also covered this theme under negative family impacts, illustrating how this barrier affects the broader family. One husband summarized how difficult the lack of centralized services made care for his wife with this statement:

“We had to go one place for the doctor, one place for the recommended tests and another for treatment. And this type of movements was most harassing for us. If we could get all the things like the doctors for specific disease, the tests and medicines at a same place, it would be very helpful for us.”

One husband made a statement of potentially great importance about needing to know someone to get care. Given the difficulties of the health care system in Bangladesh described in Chapter 4, this husband’s statement about having to know someone to receive care has serious ramifications for the disadvantaged poor from Bangladesh, suggesting that there are systems of discrimination built into receipt of care at large medical centers in Bangladesh:

“There is not any direct service anywhere. For example, I wasn't able to get my wife admitted in [major government health facility name omitted] directly. I had to do that through a medium. If a person has lobbying power, then they get free Chemotherapy and Radiotherapy at [government health facility]. But those who don't have lobbying power don't get that. I had to spend money for Chemotherapy, I didn't get it free.”

The extent to which other study participants are aware of this barrier (particularly women who rely on other family members to identify their care), is unknown.

Health System Interaction

Individuals accessing the health care system face the additional barrier of negative interactions with health care providers and the facilities. Respondents mentioning this barrier most frequently noted that the doctors, care facilities, and equipment in Bangladesh were not of high quality (n=14), that they lacked trust in the advice of doctors and consequently visited multiple doctors for opinions (n=6), that they had a bad interpersonal experience with a doctor (e.g., the doctor did not carefully listen, increased the patient's fear, or lacked of cordiality) (n=5), or that they had received bad advice from a doctor resulting in the need for additional treatment and increased costs (n=3).

One symptom of the doubt many participants felt about their quality of care is through behavior of “doctor shopping,” or visiting many different doctors, with the result of obtaining many different opinions. Some individuals who could afford to do so reported traveling to India (n=4), in some cases multiple times, to obtain treatment opinions while also visiting doctors in various parts of Bangladesh.

One woman recommended for biopsy provides an example of doctor shopping:

“...I first visited a local doctor then I went to India for treatment. After returning back from India I visited another doctor named [name omitted]. All the doctors suggested I have the operation. But one doctor in India gave me medicine for three months. To visit him I went to India a second time. When I went to India for the second time this doctor checked my chest and said, ‘I expected the tumor would soften with the medicine but still it is hard. You may need an operation.’” But he gave me medicine for the second time. This time I did not take the medicine he suggested to me. Before visiting this doctor, I went to a cancer hospital in India. The doctors of the hospital were also for operation.”

One low-cost allopathic treatment option for rural women in Bangladesh is a Christian missionary hospital, but one woman mentioned fear of conversion as a reason for not wanting to seek care there.

One husband mentioned the conditions at government hospitals as a potential barrier to care, but the statement is powerful. This husband of a woman recommended for a biopsy reports:

“...by evening there were too many patients there. That place is like a hell. I was thinking about going to a private clinic. I was even ready to sell my house to bear the expenses...I and my wife were sitting there silently, leaning against the wall like prisoners.”

Other reports of the conditions in Bangladeshi hospitals described in Chapter 4 reinforce this statement and highlight the additional burden that health facilities place on the care seeking process for breast problems.

Economic Barriers

This study identified two types of economic barriers, including inability to pay, and control of financial resources so that a woman in need of treatment is unable to pay for care.

Almost 70 percent of participants described inability to pay (the second most frequently cited barrier). Most individuals cited no funds or insufficient funds to pay for care, which resulted in no receipt of care, or only the initial visit to the doctor without the ability to afford diagnostic tests or needed operations (n=40). The mostly commonly cited reasons for not being able to afford care included having a husband who has no or low income (n=9), and a poor extended family who is unable to assist with care (n=8), illustrating women's reliance on their families to support them. Other infrequently mentioned, but potentially important influences on not being able to seek care were the cost of transport and lodging required in the process of seeking available care (n=3), poor harvests in conjunction with rising costs (n=1), not being able to discuss the disease with a family member that could help support care (n=1), and a woman not being able to work

to raise money for care due to her illness (n=1). Table 20 provides examples of statements about the inability to obtain treatment or diagnosis for financial reasons.

Table 20: Examples Illustrating Inability to Obtain Treatment or Diagnosis

<p><i>Interviewer: What is your feeling about the disease as you are suffering for a long time?</i></p> <p><i>Respondent: Because of financial crisis I cannot go for treatment.</i></p> <p>--Woman Recommended for Biopsy</p> <p><i>My husband earns so little! How would I ask him to buy me medicine? Would he buy me food or medicine?</i></p> <p>--Woman Not Seeking Care</p> <p><i>My father has died of cancer. My two brothers have their own family. So I cannot expect anything from them. And with the health condition I have, I cannot earn anything on my own.</i></p> <p>--Woman Not Seeking Care</p> <p><i>Interviewer: Don't your brothers and sisters support you with money?</i></p> <p><i>Respondent: No, How can they support me? All of them are poor.</i></p> <p>--Woman Recommended for Biopsy</p> <p><i>Interviewer: Did they suggest you to do the Biopsy test?</i></p> <p><i>Respondent: Yes, they did but I did not do it for shortage of money.</i></p> <p>--Woman Recommended for Biopsy</p>
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Among individuals who were able to initially afford a doctor's visit and diagnosis, the most frequently reported consequences of inability to pay were the receipt of incomplete care (n=12), and having limited choices in care (n=6). Though only mentioned by one individual, a husband's description of finding only one pharmacy with available medicine for his wife's treatment and the pharmacy's ability to charge high costs as a result is potentially another reason so many individuals are unable to afford

care. Table 21 provides respondent's statements about the consequences of inability to pay for care.

Table 21: Reasons for Discontinuation of Care after Initial Diagnosis

<p><i>Interviewer: Then, what was the doctor's suggestion?</i></p> <p><i>Respondent: The doctor told me that an operation was needed. But the cost was a bit too high which I couldn't manage at that time, so I returned home without the operation.</i></p> <p>--Woman Recommended for Biopsy</p> <p><i>Interviewer: Okay. What kind of help do you need for your full treatment?</i></p> <p><i>Respondent: Right now the thing I need most is money. My treatment requires a lot of money. You see I am sick. So I need to maintain a healthy diet. But I am unable to do that. Two operations, chemotherapy, blood tests—all this cost a lot.</i></p> <p>--Woman Recommended for Biopsy</p> <p><i>Interviewer: Do you have any idea why you didn't get better treatment from anywhere else?</i></p> <p><i>Respondent: Perhaps, it's because of my financial problem.</i></p> <p>--Husband of a Woman Recommended for Biopsy</p>

Participants cited poverty as a major barrier to care in general in Bangladesh, illustrated by this statement from a husband whose wife was recommended for biopsy:

"This type of treatment is a great problem for the poor people of our country. I took my wife to a well-known clinic for her operation, as there are no privileges in government hospital for this type of disease. But most people of our country cannot afford this. Even they cannot bear the cost of doctors and various tests to identify the disease."

As a result, many people rely on homeopathic medicine (or, less frequently, other forms of alternative medicine) because it is affordable for most villagers (although not always). Thirty-four study participants (54%) reported homeopathy as a consideration or first line of treatment for breast problems, and eight respondents (13%) reported that homeopathic medicine was their only option for treatment due to financial constraints. Of

note, no individual mentioned using homeopathy because he or she felt it was a better choice for treatment, although some women, described under the “Fear of Treatment” barrier, preferred it because they could avoid an operation. Furthermore, when women believe or are told there is no cure for the disease, they choose homeopathic medicine as a form of economical palliative care.

Interviewer: Have you ever taken any other steps for the treatment of your chest problem?

Respondent: No, I am a poor woman. I only take homeopath treatment.

–Woman Not Seeking Care

**Use of Homeopathy and its Influence on Delay of Care Seeking for Breast Problems:
One Woman's Story**

“One day I was lying on the bed, my hand was on my chest. Suddenly I felt something hard in my chest. I checked it carefully and became worried, as I knew about the signs of chest cancer. I became almost unconscious. However, I called my elder son and asked him to take me to the doctor. There was a homeopath doctor in our village market. He was known to us. We went to him. I explained the whole thing to him.

He told me, ‘You are thinking too much. It is not a big deal. Many women have similar problems. I am giving you medicine for a week. Take the medicine and come to me after one week. I took the medicine. It seemed the tumor became smaller in size. I went to the doctor again and he gave me medicine for another week. But this time the tumor became much bigger. I went to the doctor again and he assured me and asked me not to worry much. He gave me medicine again. I took it and found that the tumor was becoming bigger. So, after one week I went to him again. When I told him my anxiety, he also became anxious and asked to see the tumor...Then he took me inside the room and checked the tumor through my blouse. After examining it his face became dark, but he told me, “Don’t worry, you will be cured.” I came back home and then went to the government 250-bed hospital [allopathic care].”

–Woman Recommended for Biopsy

Now my husband doesn’t have any job. We don’t have fish in our fish project, no rice in the field. Because of saline water we don’t get any vegetables. There are no fruits and flowers in the trees. The situation of the whole village has become worse. I cannot explain my present situation to anyone. The price of everything is rising, including treatment expenses.

–Woman Recommended for Biopsy

Among families who are able to gather money to obtain treatment, this process can also result in delays that may exacerbate breast problems, described by the husband of a woman recommended for biopsy:

“I asked how much it will cost to do the operation at that place...He said that it will cost 6000 Taka. I told him that I was not prepared for it. I need time. I told him that I'll be back on the third of the next month.”

As mentioned in Chapter 8, families spend a great deal of time and energy trying to raise money for needed care.

Furthermore, some women (n=5) noted that resources may be available for their care, but because they did not have control of these resources, they had no options. Both women not actively seeking care and women recommended for a biopsy but were unable to obtain funds for the test reported this barrier. This exchange with a woman recommended for biopsy provides an example of her lack of control of resources:

Interviewer: What will be the reaction of your husband? Will he agree to the test [biopsy]? Will he be angry to spend the money?

Respondent: He will tell me anything and at the same time will not give me any money. He will not take any responsibility.

This exchange also hints at some recognition by the husband that he *should* be willing to treat his wife's problems (“he will tell me anything”), but that he ultimately chooses (at least from the woman's perspective) not to do so.

Attitude, Belief and Norm Barriers

Attitude, belief, and norm barriers comprise the most different variations of barriers, consisting of fatalism (“there is no treatment for cancer”), fear of breast cancer treatment, modesty about talking about the breast or talking to a male doctor, religious beliefs that influence care-seeking, stigma toward the disease, and inability of or difficulty for women to leave the home. As will be illustrated, these barriers provide insight to other categories of barriers and provide important information about the circumstances of women dealing with breast problems in Bangladesh.

Fatalism

Statements indicating fatalism were limited to those that linked an attitude of helplessness or pre-ordained decisions about their fate to not seeking care, such as “there is no cure for cancer, so there is no reason for me to seek care.” This statement by a husband of a woman recommended for biopsy sums up the attitude of fatalism he feels many people feel, but illustrates that he was able to overcome this attitude:

“When someone hears about cancer, they think that it is an incurable and costly disease and anything can happen to the patient. A sense of insecurity works in the mind. But I was too courageous and hopeful and did not feel afraid, and I tried every possible way to make her okay.”

Statements like these will be followed up on in “Facilitators to Care” described later in this chapter.

Women’s examples of fatalism were based in their own beliefs that cancer was a death-sentence. At least some and perhaps most of this fatalism is based in poverty, as illustrated by this woman recommended for biopsy:

“When my problem was first identified I was very shocked. I thought, ‘I am a poor woman, I don’t have money.’ So, I am going to die anytime.”

Other illustrations of fatalism show the interconnectedness of fatalism to not only economic barriers, but health system barriers and perhaps, more broadly, the value of women in society. Family and community members were cited as essentially saying, “What’s the point of spending scarce resources on you when you’re going to die anyway.” A sense of helplessness, protection of limited funds, and lack of concern for women’s emotional health and wellbeing are all implied by these types of statements (see quote box). One husband of a woman recommended for a biopsy appeared to invoke

fatalism in the form of God's will as an excuse not to give her money for treatment (also an instance of Economic Control described above). She notes:

"He will tell me not to go for treatment. He will say, 'It is from Allah so accept it.' Or if I call him he will tell me, 'I don't have money now. I will send you soon.' But he will never send money."

It's unclear whether this husband was truly unable to locate money, but his wife clearly understands his routine and her resulting circumstances.

"As I am not going to survive, what's the point to visit a doctor?"

-Woman Recommended for Biopsy describing her family's attitude toward her treatment

"People around me say that there's no use of treatment or operation. It will never be cured fully and the patient will die eventually; no matter how much money one spends on treatment."

-Woman Recommended for Biopsy

Fear of Treatment

Fear of treatment was the fourth most frequent barrier noted overall. Fear of operation was the most frequently reported fear among women (n=10). Fear of the biopsy (which is itself a minor operation), needles, the effects of chemotherapy, and removal of the breast were other less frequently reported treatment fears. Women reported that these fears affected their own decisions about treatment, but also mentioned the fears of their family members and husbands as influences on treatment. For example, this exchange with a woman recommended for biopsy shows the influence of her family:

Interviewer: ...what is the feeling of your family members about the test?

Respondent: They don't want me to go for the test; I mean, they are afraid.

Economic difficulties also appear to amplify fear in some (but not all) cases, as shown in this statement by a woman not seeking care:

“I am afraid of my disease, besides I do not have enough money so I am very afraid.”

Fear of operation was one reason some women (n=3) chose to use homeopathic medicine. Combined with the lower cost and easier access of homeopathic medicine, it becomes evident why many women choose homeopathic medicine as a first line of treatment.

Modesty

Modesty was reported in terms of embarrassment talking about the disease (including with the interviewer) (n=11), and discomfort in seeing or talking to a male doctor to be examined (n=6). A woman not seeking care shared her views:

“My problem is with the male doctor. I can't tell them everything in detail. So I won't blame them because if I don't tell them clearly then how will the medicine work! Female doctors would make this easier to treat.”

Two husbands also reported their own modesty about the issue (with ramifications for men's knowledge about the disease, discussed later in this chapter), illustrated by this statement:

“Discussing about this kind of private matter is not something a gentleman does. I don't think we can discuss about this thing even with a close friend...as it is a matter of breast, a sensitive organ, no gentleman will be eager to know that.”

Modesty may also affect women's ability to access resources for care, as noted previously under economic barriers. One woman not seeking care noted that she could not tell her older son about her problem, and thus could not ask him for money for treatment, even though he is already spending money for his father. She stated:

“Their father is an invalid and for his treatment, my son, working away from home, is sending us money. But, I cannot get any help because it [her breast problem] is a secret and cannot be shared with my son.”

This exchange with a husband of a woman recommended for biopsy illustrates that, in his opinion, modesty is widespread in Bangladesh, potentially more so than this study revealed:

Interviewer: Is there any tension in our society about what people will think if we reveal a disease like breast cancer?

Respondent: Yes. People feel ashamed or uneasy sometimes. To tell the truth, 99% people of our society have this uneasiness.

Religion

No study participants cited religion as a barrier (consisting of citations of a particular religion or religious text as a reason a woman was not seeking care). This finding may be the result of the lack of direct interview questions about the role of religion, or the specific inclusion criteria for the code, the implications of which will be covered in the discussion.

Stigma

Study participants reported stigma, including descriptions about why individuals enact stigma and the outcomes of stigma specifically towards breast cancer, in smaller numbers than would have been expected given earlier reports from Bangladesh (Table 20). In all cases of stigma identified, respondents indicated that breast cancer was responsible for the stigma felt or experienced.

Three main forms of stigma were identified in this study, including thinking the woman infected with breast cancer is a “sinner” (n=5), “bad” (n=4), or infectious (n=3). Quotes to illustrate each of these types of stigma are provided, below.

This study identified a form of stigma in which Muslim study participants felt that Allah was punishing women for sins via their breast problem. Five individuals reported this type of stigma using phrases such as “I repent to Allah about my sin,” “Let’s see if Allah forgives me or not,” “Allah can forgive it, but if not, people will die,” and “We thought that Allah might have forgiven us.” One additional husband of a woman recommended for biopsy indirectly referred to this type of stigma, saying, “She used to say her prayers regularly. So, I can say that she has not committed any sin.” Reference to Allah ties this form of stigma to Islam. However, it is coded stigma for its potential to devalue women with breast cancer as sinners or bad people, the next theme discussed in this section.

Two men and two women reported stigma in the form of thinking a woman was bad. This statement from a husband of a woman recommended for a biopsy summarizes this attitude:

“...people have a bad impression of this disease. They may think the victim to be a bad person.”

Another husband reporting this type of stigma suspected that his wife might fear stigma from him, stating:

“...I used to speak very softly and tried to console her, because she used to think that her husband might not be taking this easily and thinking something bad about her. So I told her not to worry much and she will be fine very soon by proper treatment.”

One woman reporting this type of stigma did not have such a supportive husband and was divorced for her disease. Table 22 illustrates this woman’s story. Her circumstances illustrate the following: 1) the conditions in which stigma occurs, 2) the impacts of stigma and emotional abuse on seeking care, and 3) how she was able to deal

with these circumstances and ultimately see a doctor for diagnosis. Her story shows that women who have control of resources (financial, in particular) also have more control of their health and better ability to deal with the impacts of stigma, but are still quite vulnerable.

Table 22: Case Study of Rehana, a Woman not Actively Seeking Care for a Breast Problem

Rehana [named changed for privacy] is a 28 year old homemaker with employment as a housekeeper. At her first interview, she had been suffering from an abscess on her breast for about a year. She was aware that she needed to see a doctor and that she could find treatment in village through a visiting doctor. Her husband, however, would not approve of her going for treatment. When asked why, she said, “He is a village person. Village people do not want their wives to go outside.” She went on to elaborate, “...he and his family didn’t want me to go out. They didn’t want any other person to know about my problem. But I was suffering.”

When asked what she thought other people in her society felt about breast disease, she said, “They have misconceptions about it. They think the woman is bad who has breast cancer,” and also said that she felt that husbands and mother-in-laws who were “good” would take responsibility for women with breast problems, but if they were “bad,” they would not, and would feel it was wasteful to spend money on treatment.

By Rehana’s three-month follow-up, she had managed to see a doctor on her own without the support of her family members, but indicated that her husband had separated from her as a result of her breast problem, and that she was now living with her brother, despite an encouraging diagnosis from the doctor. She expressed that her extended family wanted her to see a doctor, but that “...they do not want to involve themselves into this problem. They do not care for me.” She indicated that they knew nothing about her diagnosis. Rehana’s biggest concern was finding money to pay for additional transport and treatment costs.

Rehana’s story illustrates the impact of stigma against breast problems (even the threat of breast cancer among undiagnosed women) and her vulnerability as a result of traditional gender roles, social norms and an unsupportive husband and in-laws. Her husband and his family cast her out of her home and emotionally abandoned her. Compared to many women interviewed, however, Rehana was knowledgeable, had a family member who was willing to take her in, and, importantly, had employment from which to pay for basic medical care and medications. This latter fact in particular gave her the resources for initial transport and doctor’s fees. It is less clear what factors gave her the courage to overcome stigma and the belief that women should not leave the home, but perhaps her husband’s attitude gave her no choice but to fend for herself. Unfortunately, if Rehana should ever warrant more advanced breast cancer treatments, she may not have sufficient resources or support to do so.

Of the three individuals reporting stigma about breast cancer being infectious, only one person had personally experienced this stigma. This husband of a woman who

needed extensive care in the capital city of Dhaka recounted stigma toward his wife in the form of relatives believing she was infectious:

“Her diet, her clothing everything was fine. But just because of that disease, everyone started being distant from her. They were helping me as I am their brother. But they were afraid of their brother's wife. They were not willing to help her. They thought that if they interact with my wife then they might catch the disease as well. The kids might be affected. Our next generation might also be affected. These are the reasons why they didn't want her to stay in the same house. They gave money, they rented a house for us, but they weren't willing to keep her in their house.”

This statement illustrates that individuals may even be willing to help (be a facilitator), but because of their stigmatization of the disease, prefer to physically stay away from her. The remaining two reports of breast cancer as contagious specifically noted that people would “stay away from her” and that she was “infectious.”

There was a single instance of a woman recommended for a biopsy who mentioned that her neighbors thought she had developed a breast problem because she no longer had physical relations with her husband (she was divorced prior to developing her breast problem), stating:

“Some people told me that it's because I don't have any physical relation with my husband; that's why this problem has developed.”

Finally, there were five ambiguous cases of stigma. The following exchange with a woman not seeking care illustrates this ambiguity:

Interviewer: The other family members behave badly with you?

Respondent: They don't say anything in front of me, but I can understand from their attitude that they don't like me for my illness.

These types of statements were initially coded as stigma, but were not ultimately included in the counts of stigma due to lack of further follow up to understand more about why this attitude arose.

Women's Inability to Travel outside the Home

Three women not seeking care mentioned the inability to leave the home (including Rehana in Table 20), or inability to leave the home without a chaperone as a barrier to care. One woman not seeking care shared that not only was her husband not interested in going with her for care, but that she also did not feel comfortable letting someone else know about her disease, which would be required in this case if she were to go for care. She stated:

"The matter is, my husband isn't interested in going along with me to the doctors. He tells me to go with others, but is it not always possible to share private problems with others."

This statement suggests a link between attitudes about women traveling outside the home and modesty about breast problems.

Rehana, described in the case study in Table 21, attributed her difficulties in seeking care to her husband's perspective:

"He is a village person. Village people do not want their wives to go outside."

I cannot go to a stranger without my dear ones. Moreover, I don't go outside alone.

–Woman Not Seeking Care

That only women *not* seeking care named this barrier, suggests that this may be an important reason some women never seek care, or delay care until family members can no longer ignore a breast problem.

Knowledge Barriers

Knowledge barriers, particularly lack of knowledge, were the most commonly reported barrier to care, reported by over 75% of all study participants. Knowledge barriers were often relatively straightforward statements from study participants about knowing little or nothing about breast cancer, but also encompassed statements about not knowing about the types of care that existed.

Descriptions provided by study participants about the general level of knowledge in Bangladesh revealed widespread ignorance, such as this statement from a husband of a woman recommended for biopsy:

“Women, whether they are educated or uneducated, know very little about this kind of disease. I have talked with a lot of village women who do not know a single thing about this topic.”

Another husband of a woman recommended for biopsy described the difficulties people generally face in getting care:

“Nowadays, this disease has spread out a lot. It is heard in many places. But everyone is in a hesitation or harassment of what to do, where to go, because they do not have the proper knowledge of it. They don’t know where they should go. Nothing is certain.”

Twenty-four individuals (23% of the total study population) used phrases such as “I have no idea” or “I have little idea” when asked about their knowledge of breast cancer and its treatment, illustrating a complete lack of awareness about the disease.

“Most of the people of our village don't know anything about this disease. Only the people who face it, understand it”
–Woman Recommended for Biopsy

One woman recommended for biopsy described their lack of knowledge about breast cancer in connection to her understanding of other breast problems:

Interviewer: Had you ever heard about this disease before you got it?

Respondent: No. I only knew about chhar and goirachor.

In other cases, women noted that they did not realize their breast tumor was abnormal, as in this exchange with a woman recommended for biopsy:

Interviewer: What did you think when you first identified the problem?

Respondent: I did not know anything about this. I thought every woman has this type of hard thing inside their chest.

Society appears to inhibit women's exposure to knowledge of any kind after marriage, which may be an important insight for determining how to reach married women. An exchange with a woman recommended for biopsy illustrates this issue:

Interviewer: Do you have any idea about the chest disease?

Respondent: In my student life I had contacts with doctors. After getting married I have to squeeze myself. Hope you can understand it. It is our culture for the married woman.

This lack of knowledge, unfortunately, also meant that women had no idea how they should deal with breast problems, as shown from this exchange with a woman recommended for biopsy:

Interviewer: What steps can you take to help you to live better with this disease? What can help you to continue your treatment?

Respondent: I have no idea what could be helpful for me. So, I cannot say.

Another woman recommended for biopsy referenced the conflicting information she heard after her diagnosis, which led to confusion about how to proceed:

Interviewer: Please tell me from your experience, what type of initiative can make the treatment of chest cancer easier?

Respondent: Now, you tell me how I can get good treatment? Some people say if I could have an operation it would cure me, some people say the opposite. I don't know what to do.

Interviewer: So, do your children or other family members have any kind of awareness about this?

Respondent: No, it doesn't seem so. I don't understand anything so I don't visit any doctor.

–Woman Not Seeking Care

Two women recommended for biopsy and one husband of a woman recommended for biopsy provided explanations for this widespread lack of knowledge about breast cancer. One woman felt that non-governmental organizations were focusing on health promotion of other diseases such as diabetes instead of breast cancer, while the other woman reported that health organizations no longer visit village homes to promote health awareness, meaning that awareness of any disease is lower than it used to be. The husband, also quoted in Chapter 8 in the description of abuse, ascribed the lack of awareness about breast cancer to societal male dominance, leading to the neglect of women's issues at all levels.

Eighty-five percent of men reported similar knowledge barriers to women, but in three instances, men's responses took on a different tone, which appeared to be related to a belief that breast problems were not something they should be privy to, despite their important role in helping their wives seek care. Exchanges with husbands about knowledge sounded defensive, including these two examples:

Interviewer: Then I am going to ask you one last question. If you know, can you tell me about symptoms of breast cancer?

Respondent: This is none of my concern. How can I give you an overview regarding this?

Interviewer: Okay, do you have any idea about the symptoms or signs of breast cancer?

Respondent: No, I am not the doctor so I don't have any.

One potential explanation for the overall lack of knowledge came from a woman recommended for a biopsy who said, *“NGOs work for diabetes awareness, you know. But no one talks much about breast cancer.”*

Exclusion from Knowledge

Two husbands also described excluding their wives (or doctors excluding their wives) from discussions about her diagnosis. One husband described how this exclusion occurred:

“He [the doctor] checked her out. Then he told my wife to sit in another room and talked to me privately. He told me that this patient is beyond his capacity. He referred us to another doctor in Khulna.”

One woman recommended for biopsy also describes this exclusion in terms of others not using the word ‘cancer,’ though her condition was still apparent to her:

“Yes, I was really afraid when they told me that my situation had turned to cancer, although they did not utter the word ‘cancer’ they said that my situation had already become bad.”

These descriptions of knowledge together illustrate a broad lack of knowledge, confusion about what to believe, belief that breast health knowledge is not within a man’s domain, and purposeful exclusion of women from knowledge about their breast problem, which can and has led to critical delays in treatment of breast problems.

Other Disease

A barrier not identified a priori, but that emerged from interviews of four women recommended for biopsy and two women not seeking care, was the existence of diseases requiring immediate control or given higher priority before treating breast problems. For

example, one woman recommended for biopsy faced uterine and breast problems as well as complications of diabetes, and was initially sent home by her doctors and advised to lose ten kilograms before she could be treated for her other problems. This type of delay in care may be necessary, but also deadly in the case of aggressive breast cancer.

Other Barriers

Additional “other” barriers with single cases (n=7) are tied to an inability to find needed support, either from the community or from within the family. One example included a general lack of support from others cited by a husband of a woman seeking care. Women’s lack of control over resources and reliance on her husband for support comprised the remaining two examples. One woman recommended for biopsy had an elderly husband who was not able to support care. Another woman had a husband whose health problems, in her opinion, should take higher priority (also based in financial concerns). Furthermore, her polygamous marriage complicated the situation. This woman, who was not seeking care, stated of her husband’s heart trouble:

“How would I ask for treatment of my problem like this in front of that problem?”

She also noted:

“Had I been the only wife, I could have asked my husband to sell 5 Kathas [3600 square feet] of land, but he has two wives. So I cannot even ask it.”

While it does not appear that polygamous marriage is common in the Khulna Division, it appears in this case to be an important consideration in the distribution of scarce resources.

Abuse and its Association with Care Seeking for Breast Problems

Chapter 8 provided examples of abuse, primarily emotional abuse. While this study cannot conclude that abuse plays a role as a barrier to seeking care, both the survey and interviews with women illustrate that women not seeking care more frequently report abuse of any type (physical, sexual and emotional) than women recommended for a biopsy at a breast care center (Table 23).

While no statistical difference was found between these groups, there is other evidence to suggest that this difference could be significant with a larger sample. For example, only women not seeking care reported not being able to leave the home unaccompanied. This finding suggests that women not seeking care may be from conservative families that identify with strict gender roles. Chapter 5 illustrated that strict gender roles and threats to these identities posed by a diagnosis of breast cancer were an important contributor to violence against women.

Table 27 in Appendix G also suggests that women not seeking care were from lower income families than women recommended for biopsy, and women not seeking care may be more similar to women in the Khulna Division than women recommended for biopsy. Chapter 5 also identified resource strains as a factor in violence against women, which further contribute to threats to gender identity.

Ultimately, these suggestions require additional study to conclude that women not seeking care for breast problems experience greater abuse than women actively seeking care. However, the potential significance of such a finding warrants abuse and the factors related to increased abuse as important considerations.

Table 23: Types of Reported Abuse by Whether a Woman is Actively Seeking Care for a Breast Problem or Not

	Women Not Seeking Care n=24	Women Recommended for Biopsy n=19
Physical Abuse in Prior 3 months*	8 (33.3)	3 (15.8)
Sexual Abuse in Prior 3 months*	2 (8.3)	0
Narrative reports of abuse by family (any type)	13 (41.7)	5 (26.3)

*Physical abuse in the prior 3 months and sexual abuse in the prior 3 months was missing for two women not seeking care

Facilitators of Breast Biopsy

Facilitators of care enabled women with breast problems to overcome barriers to care, which theoretically should have the effect of increasing women's ability to receive a biopsy for breast problems among women recommended for biopsy. Table 24 provides groupings of facilitators of care for individuals who received a biopsy.

Table 24: Facilitators to Receipt of a Breast Biopsy among Study Participants Receiving a Biopsy

	Women Receiving a Biopsy (n=12)	Husbands of Women Receiving a Biopsy (n=20)	Total (n=32)
Encouragement and Support			
From Husband	11 (91.7)	14 (70.0)	25 (78.1)
From Other Family Members	10 (83.3)	4 (20.0)	14 (43.8)
From Friends and Neighbors	4 (33.3)	1 (5.0)	5 (15.6)
Knowing Someone to Gain Access to Services	0	5 (25.0)	5 (15.6)
Economic Support			
Financial Support/Selling Assets/Identifying Other Forms of Financial Support	4 (33.3)	6 (30.0)	10 (31.3)
Paying Extra to Get Faster Results	0	1 (5.0)	1 (3.1)
Finding Lower Cost or Free Care	2 (16.7)	1 (5.0)	3 (9.4)
Exposure to Knowledge that Reduces Fear, Modesty, or	11 (91.7)	8 (40.0)	19 (59.4)

Increases Awareness of the Problem			
Belief that Disease is a Test of Faith to be Overcome	1 (8.3)	2 (10.0)	3 (9.4)

*All but one woman in this group are women recommended for biopsy at the baseline interview. One woman not seeking care went on to seek care, be recommended for a biopsy, and receive a biopsy and is thus included in this count.

The most frequent facilitators described by participants included support from the husband and husband's family, identifying or making arrangements for financial support, and information and advice provided by others. These and other facilitators to overcoming barriers to care are described, below.

Encouragement and Support

Encouragement and support was the most frequently named facilitator among individuals who received a biopsy, particularly the support of the husband and in-laws, followed by support from other family members and friends. One woman who received a biopsy describes her husband's support as vital to her treatment:

Interviewer: Your family members knew about your problem. So they helped you at your treatment time? Or was your husband with you at your treatment time?

Respondent: Yes, my husband was with me and my treatment would not have been possible without him. He was my guide and he took care of every aspect of my treatment.

Husbands of women who received a biopsy, by nature of their willingness to take her for diagnosis, were supportive of their wives' need for a biopsy, but also made statements to this effect in many interviews. One husband, whose wife died from her breast cancer before the follow-up interview, expanded on this by explaining that his marriage was not arranged (as are many marriages in Bangladesh), but was a mutual affection between he and his wife:

"We married each other because we liked each other. After God it was my responsibility to take care of her. I tried my level best. If she was alive I had to take care of her as long as she would live."

This statement is in stark contrast to those of women reporting neglect, indifference, and abuse from their husbands and in-laws, and is an example of a woman being valued for her personality as opposed to her role in the household. This type of value clearly facilitated her care, despite her unfortunate death. This story, highlighted as a case study in Table 23, shows that even when women have the support of their husbands (which is a significant barrier for some women), there are still many barriers that delay care and lead to poor outcomes.

Table 25: Case Study of Halima and Her Husband Rafiq

Halima [named changed for privacy] was a 34 year old college educated, married mother who emphasized her dual role as a homemaker and worker in a leather factory. She described herself as having to “squeeze” herself after marriage when it came to exposure to new information, particularly about breast cancer and its treatment. When Halima first recognized her breast problem, she went to a homeopath because she knew a few women in her village and had a sister who had successfully treated breast problems with homeopathy. During the course of homeopathic treatment, her tumor grew, and eventually ruptured through the skin, hanging as a soft painless mass from her breast. She decided to seek treatment because friends told her she needed antibiotics to clear up the infection on her breast, and she was experiencing pain in her arms and legs, and difficulty bending down for her daily prayers. It was at that point that a doctor recommended her for a biopsy, but she expressed no regrets in her decision to use homeopathy. Halima noted that her husband was supportive of her treatment.

In the three months between interviews, Halima’s condition deteriorated and she died. Halima’s husband, Rafiq [name changed for privacy], was interviewed to learn more about Halima’s unfortunate death.

Rafiq recounted Halima’s choice to see a homeopathic doctor, despite his objections. It was not until the tumor ruptured that she agreed to see an allopathic doctor. Rafiq expressed that he would have done anything possible to save her. He states, despite some initial discomfort from his parents, “We married each other because we liked each other. After God, it was my responsibility to take care of her. I tried my level best. If she was alive I had to take care of her as long as she would live.” He went on to add, “We loved and trusted each other. So, with that love and trust wherever she wanted to go for treatment I tried to take her there.” Halima’s husband described organizing money from a friend in Saudi Arabia, receiving money from Halima’s colleagues, and leaving her gold ornaments as collateral on a loan so he could pay for treatment.

Halima is a rare example of a woman who married for love, and through that love, received the unwavering support of her husband in a time of crisis. Unfortunately, her lack of knowledge about breast cancer, possibly facilitated by a gender identity and social norms that discouraged her from exposure to new information, led her to delay seeking allopathic care until her tumor was at an advanced stage. Despite her husband’s support and ability to raise funds for treatment, Halima lived only a short time after entering the allopathic health care system, and perhaps never recognized the severity of her disease until shortly before her death.

It is important to note, however, that individuals can be both facilitators and barriers, as in the case of this husband who recounted an instance of how his brother's family reacted when they learned about his wife's breast problems (and described under "Stigma" in Chapter 8):

"...They gave money, they rented a house for us, but they weren't willing to keep her in their house."

Finally, while homeopathy was more frequently discussed in relation to barriers to care, two women noted that homeopaths played an important role in recommending allopathic care, as shown in this exchange:

Interviewer: The homeopathy doctor gave you an ultrasonography?

Respondent: He sent for it. I went to Khulna. They said I have a problem in my blood. The homeopathy doctor said that there are many problems in my breast; it may turn into a cancer.

Homeopaths, who can recognize when breast problems are outside of their ability to treat, have potential to ensure that allopathic doctors see women with symptoms of breast cancer as early as possible.

Knowing Someone to Gain Access to Care

Only men reported using a contact to gain access to care. In the instances recounted, men called on friends, family members, and professional acquaintances to help ensure a doctor in busy health facilities saw them where they might otherwise wait indefinitely. This husband describes how he gained access to needed radiation treatment for his wife:

"Financial support is needed but I received some political backup for my wife's treatment. When I went for the radiotherapy after my wife's operation, my serial was first [he and his wife were the first to be seen] and I got treated like VIP there."

Economic Support

Economic support was, not surprisingly amongst this resource-poor rural population, an important facilitator. Individuals named financial support or loans from friends, family and community members, selling land and property (see examples described under “Family Impacts” in Chapter 8), paying extra to get results faster, and finding lower cost or free care all as economic facilitators.

One husband described how he was able to arrange money for his wife’s operation and medicine:

“Look, I’m a poor guy... Two or three days ago, for my wife’s operation, I had to buy medicine that cost me a few thousand taka. A woman named [name omitted] helped me with about 12 thousand Taka. I also sold my livestock to arrange that money.”

One woman recommended for biopsy who found lower cost care mentioned:

“I had no money, so I went to a Church for my treatment. I could not go to any better place...In the Church, it took only two thousands taka to complete the treatment, and they were very careful to their patients. The sisters and the doctors were very much caring, responsible, and attentive to their patients.”

The additional benefit of having “caring, responsible, and attentive” health providers may have also helped to overcome health system interaction barriers reported by some women.

Increased Knowledge and Awareness

Women in particular, mentioned the receipt of information and advice about breast problems and treatment from friends, family, and neighbors more frequently than men did. Men, on the other hand, discussed exposure to knowledge and information that helped to reduce fear and modesty, or increase awareness of the problem. One husband shared how he overcame his modesty with education:

“People feel ashamed or uneasy sometimes. To tell the truth, 99% people of our society have this uneasiness. But me and my wife, we are very openhearted. We are like this, not

only between us, but also for everyone else. We don't feel uneasy to talk about anything with anyone. When I was a university student, I attended few seminars of British Council which helped me to come over this uneasiness."

One individual named family history of breast problems as a reason she knew about symptoms and sought care.

Belief that Breast Problems are a Test of Faith

Three individuals who received biopsies named the belief that their disease (or their wife's disease) was a test of faith that they had to overcome. A husband of a woman recommended for biopsy who received one, discussed his feelings about the disease, said:

"I didn't feel angry, because diseases and illnesses are examinations for us from God."

A woman who received a biopsy also mentioned:

"Listen, when the God sent me to the Earth, he has a plan for my death. I cannot flee from that. He knows how will take the life of a man. He knows better than us as he created us. Maybe He put me in this situation to test my faith. I believe I will get rid of this disease."

Far from being a barrier, religion in this case, particularly the belief that disease is a test from God, acted as a motivator to find care and recover, thus illustrating the faithfulness of the believer.

The Cross-Over

The sole woman who was not seeking care at the baseline interview but who went on to have a biopsy appeared to have a supportive husband and mother-in-law, and was encouraged by a woman in her neighborhood who had breast problems, as well as the interviewer, to seek care. She originally did not seek care because husband "husband did not stay at home," but it is unclear if this meant she could not go for treatment without her husband or did not feel it was important enough to discuss with other relatives.

Becoming a Facilitator through Experience

One additional finding not reported in Table 23 is that both women and husbands of women who received a biopsy reported that they themselves became facilitators of care by providing information and advice to family members and people in their community. A husband of a woman referred for biopsy noted:

“...one good thing is that now I can suggest to people where they should go, to whom they should go, etc. One day a gentleman came to me asking about my wife. His daughter has the same issue. His daughter was newly married and he was worried about her. I referred him to Dr. [name omitted]. I also suggest people to be frank in regard to this problem and seek treatment as soon as possible if any symptom is noticed.”

Furthermore, a woman who received a biopsy conveyed how she believes her experience is helping others:

Interviewer: If there is a breast cancer patient near your home what do you think their family members will say? Will they encourage her to take treatment? Or will they say that there's no need to waste money?

Respondent: I think they will help. They saw me and they are learning something from my situation.

Discussion

Abuse, in the form of physical and even more frequently emotional abuse, appears to be a widespread phenomenon, as illustrated in Chapter 8. The literature and population-based surveys of abuse or violence typically focus on the extreme cases of physical abuse (which clearly does exist in Bangladesh in large numbers). However, many women appear to experience regular emotional abuse or neglect by their immediate families (husband, in-laws) which may be a symptom of societal attitudes toward women and exacerbated when she can no longer enact her role as a rural Bangladeshi woman because of her disease. Though not a statistically significant difference, this symptom appears to have a relationship with care: Approximately twice as many women not seeking care reported physical or emotional abuse than women seeking care (and recommended for a biopsy), and women not seeking care were the only ones to report any type of sexual abuse. Women not seeking care were the only ones to report not being able to leave the home for care, suggesting they were from conservative families with potentially stricter gender roles. They also may have come from families with fewer resources and be more similar to women representative of the Khulna Division. Chapter 5 showed that both of these factors (gender identity and scarce resources) contribute to violence against women.

Further study is required to clarify these findings, and potentially essential for effective breast cancer awareness and detection efforts. In terms of quality of life and disease outcomes among women experiencing breast problems, those experiencing physical and emotional abuse appear to be particularly vulnerable. Attitudes of indifference and neglect of women, in particular, impart a sense that women are not

valued beyond their ability to conduct household duties. Some evidence suggests that husbands, with the support of their parents and extended family, will replace women as wives when women cannot complete these duties. Without a recognition of the serious consequences of breast problems on women's lives, breast cancer programs may not reach a substantial number of women with breast problems.

The three study groups bring together three different perspectives on the barriers and facilitators of care in rural Bangladesh, providing rich insights to the challenges faced by women and families dealing with breast problems, particularly in light of the context provided in Chapter 8.

The barriers identified in this study appear to support the literature on barriers to breast cancer care, as well as add some additional insights and contradictions, described below, that may be specific to rural Bangladesh or to other similar countries.

As a starting point, there is obviously still a great need to increase knowledge and awareness of breast cancer, including its symptoms, screening behaviors, the existence of treatment facilities, (including low-cost options) and in the process to reduce misconceptions and stigma (e.g., "breast cancer is contagious"). The support of husbands, however, was highly important to receiving care *despite* husband's reports of their lack of knowledge. Husbands may provide additional support if they know how to recognize symptoms of breast cancer, and where to go when those symptoms arise. As noted by one woman, her access to information became limited after marriage due to social constraints, so the husband, as someone who is freer to move outside the home, may be an important source of information for low-resource families unless these norms change or other ways of reaching home-bound women are identified. Numerous women and men said they did

not initially think the breast lump (or other symptom of breast cancer) was something about which they should worry. Reducing the delay caused by this lack of knowledge has the potential to improve quality of life and save lives. Ensuring women are part of the conversation at each stage of their diagnosis and treatment will help ensure that she makes choices in her best interest.

Explanations for lack of knowledge about breast cancer also suggest that there is a lack of awareness about disease in general, but also that, as a woman's disease, societal attitudes towards women impacts national health policy and results in fewer health promotion efforts for breast cancer. This finding has ramifications for larger-scale efforts to build awareness about not only breast cancer, but also other women's health issues.

Study results emphasize the role of economic barriers, particularly in this resource-poor setting of Bangladesh. The belief that no effective care can be received within the family's budget, inability to raise funds, and lack of availability of low-cost or free treatment prevent many families from seeking care, especially if it means that the entire family will suffer. Furthermore, women's lack of control over resources and infrequent paid employment mean that some women who may otherwise want to seek care cannot do so, even when their husbands have funds to access treatment.

Religion was an important potential barrier to explore, but given the literature on the positive role that Islam, in particular, can exert on health promotion efforts described in Chapter 3, it should not be entirely surprising that it was not directly mentioned as a barrier. In fact, given the positive role that faith played for at least two recipients of a biopsy, Islam may be useful for invoking increased breast cancer awareness efforts in Bangladesh. Some other barriers, however, hinted at the role that religion might play as a

barrier, despite the code not being identified. The literature connects modesty, for one, to Islam's prohibition of female nudity with anyone but her husband. Another barrier noted by some women and sometimes attributed to Islam was that of not being able to go outside or to go outside alone. Information provided in Chapter 3 also suggests that attributing this attitude to Islam may be an incorrect interpretation of the Qur'an. One female study participant specifically noted that it is "village people" who do not want their wives to go outside, as opposed to "Islamic people," thus illustrating that religion is not the first thing that comes to some people's minds as a barrier, and suggesting that Islam may not be the root of these attitudes and behaviors. The fact that women do not feel they can reach *available* care, however, is one that Bangladesh health promotion efforts still need to address. Finally, reports of stigma (discussed in more detail, below) included a sub-theme of feeling that breast cancer was a punishment for sins. Together, these three findings and reports of Islam as a facilitator suggest that Islam can have both positive and negative influences on care seeking, and that breast cancer awareness and treatment efforts in Bangladesh may benefit from addressing these issues thru the lens of Islam.

This study also identified the use of homeopathy or other alternative forms of medicine as a first line of treatment due to its lower costs and close proximity to study participant's homes. A unique finding of this study, however, is instances in which a homeopath recognized his limitations in diagnosis and treatment and referred the study participant for allopathic forms of care. Given the widespread poverty in rural Bangladesh, it is unlikely that women will give up the use of homeopathy for more expensive and often less accessible allopathic care, but homeopaths may be useful

conduits for promoting breast exam and identifying and referring women with signs of breast problems. This could be beneficial to women through reassurance to the majority of women who have benign breast problems that they are fine, and increase the number of women with more suspicious breast problems that seek allopathic care. With already overburdened health care systems in Bangladesh, it is important not to send a flood of “worried well” for examination to allopathic providers when initial screening might be competently done, at least in part, via trained homeopathic doctors.

Also shown in this study, having another disease, particularly diabetes, can significantly delay or prevent treatment for serious breast problems. Diabetes is a common disease in Bangladesh for both men and women, and is generally more acceptable to talk about, particularly as a disease associated with affluence. There are also designated, well-funded treatment centers for diabetes with specialized doctors in the country. Thus, women with diabetes (and potentially other chronic diseases affecting both men and women), are more likely to find doctors eager to treat diabetes as opposed to a less common, less understood, and less socially acceptable disease such as breast cancer. This finding also stresses the importance of preventative health to reduce incidence of diseases that can more easily be prevented through changes in lifestyle, thereby giving women with breast problems a better chance (through fewer competing illnesses) at early and successful treatment.

Stigma (a devalued identity directly linked to the experience of having breast problems or breast cancer, and a difference in actual versus virtual social identity) was identified as a barrier to care in the literature and was an elicited barrier during participant interviews. For this reason, it was surprising that this study did not find more

cases of stigma among this population. In fact, one extreme case of stigma involved a brother's family in Dhaka city (not rural Bangladesh) who would not allow the wife into their home for fear of contagion.

Stigma, however, appears to be an additional source of emotional abuse, including divorce. Divorce, in particular, for a woman who has few resources of her own and faces a life-threatening disease, can have devastating emotional and physical outcomes for women in the absence of other supportive and economically stable family members.

This study highlights the often blurred lines between what constitutes stigma and what are effectively harshly practical reactions to serious disease in the absence of effective, affordable health promotion and treatment. In a culture with rigidly defined gender roles and low value of women by international standards, women who are unable to fulfill their roles and have few options for treatment take on a reduced status and, in some cases, cast out and replaced by family members. Efforts to justify this treatment are found not only in the "why" of stigma (she is "bad," a "sinner", or "contagious"), but the fact that she is a drain on already scarce family resources, and that she is ultimately going to die anyway. Many diseases could have similar impacts on women and their families, particularly in impoverished areas of Bangladesh. This study would suggest that, although there are specific instances of stigma about breast cancer that may influence care, there are many other, perhaps equally or more influential factors that create challenges for women and their families when dealing with breast problems or breast cancer, and that these challenges may be faced by women with other serious diseases.

CHAPTER 10

CONCLUSIONS AND RECOMMENDATIONS

This study adds to the sparse literature on factors that influence South Asian women's decisions to seek care for a breast problem. In particular, this study contributes to understanding populations not typically included in studies on barriers to care, including women living in rural areas, women not actively seeking care for a breast problem, and men who often play an important role in decision making on issues related to receipt of care. While barriers to care identified in this study largely support the literature on barriers to care in South Asia, this study also provides some distinct perspectives of significance for barriers in Bangladesh. These perspectives, in particular, challenge the barrier of stigma and illustrate how many of the barriers identified among this study population are reflective of two broader themes: structural violence and the value of women in society. Additionally, this study aids in our understanding of abuse in the lives of Bangladeshi women with breast problems and offers questions for future consideration.

First, as a topic of interest to researchers globally, and as a barrier identified previously in the literature in Bangladesh, it was unexpected to find so little stigma in this study. Overall, stigma was the eighth most frequently mentioned barrier.

Stigma primarily took the form of men and women reporting that others felt women with breast cancer were “sinners,” “bad,” or “contagious.” There also existed one reference to a woman's divorce as a reason for the breast problem. Outcomes of such attitudes were that women experienced negative feelings (potentially a form of emotional

abuse), were cast out from their husband's home and divorced (active emotional abuse), and in one case were not permitted to stay with family members while receiving care in Dhaka city. Each of these examples supports Else-Quest and Jackson's (2014) descriptions of the impacts of cancer stigma on the patient, including isolation, shame, self-blame, and guilt.

The relationship between religious attitudes (specifically Islam) and stigma is an interesting study finding. Both the literature on the health promoting aspects of Islam, as well as some statements by study participants, illustrate that Islam can be a facilitator for seeking care for breast problems, despite the references to Islam identified in instances of stigma. Breast care efforts may thus draw on the health promoting aspects of Islam to counter the stigma attributed to believing breast cancer is a punishment for sins.

Stigma has also been described by authors Yang, et.al (Yang et al., 2007) as a rational response to a threat, stemming from things that threaten what matter most to individuals and serving a protective role. While this explanation for stigma has unacceptable effects on women with breast problems, it frames stigma in a way that suggests that dealing with other barriers to care may reduce or eliminate stigma. Thus, efforts to address stigma may require a well-rounded understanding of the barriers to breast cancer care faced by women and their families, one that this study provides for Bangladesh.

Overall, it is clear that women with breast problems in rural Bangladesh face stigma as a barrier to breast cancer care—just not to the degree expected. The impacts of stigma have the potential to prevent care seeking for treatable disease, leading to poor outcomes for women and their families. As a result, further study is warranted, and breast

care programs would be prudent to address this issue, as well as other existing barriers, directly with their target audience. Future studies may incorporate specific examples of stigma previously identified in the literature to confirm whether the attitudes identified in this study are more widespread and whether additional types of stigma exist.

Many barriers, including potentially stigma, point to a broader theme arising from this study, that of structural violence first described by Galtung (1969) and later by Farmer (1996; 2010). One of the most frequent forms of structural violence illustrated by this study was poverty and its impact on the treatment of breast problems. Even individuals who were actively seeking care (versus those who were not) discussed difficulties paying for care. This fact, however, should not be surprising, given the low-income status of Bangladesh and the more rural nature of the sample. As a form of structural violence and a fundamental cause of poor health, poverty affects many areas of a family's life. As noted by some women in this study, other illnesses (both their own and their husband's) in addition to their breast problem strained limited resources, and in some cases meant their breast problems were not prioritized. Study participants also cited the inability to pay for care as a source of concern and emotional stress for the family. When men are expected to be the providers for the family and are unable, via limited resources, to do so, the theoretical construct of threats to gender identity in violence research would suggest a resulting increase in violence toward women, particularly within the context of a male-dominant society. It is thus not surprising that women cited having to spend money on her care as a reason for emotional abuse, including abandonment.

Poverty also influences the power that individuals hold in society. One person (a husband of a woman recommended for biopsy) mentioned a serious barrier to access of government health services, that of having to have “lobbying power” with hospital officials in order to receive care and reduced costs for care. Individuals without such power (namely, less educated, rural poor; those who most desperately need reduced cost services) are clearly at a disadvantage in this respect. This form of discrimination is a clear example of structural violence affecting a specific group of people in Bangladesh (rather than society as a whole) and affecting the health outcomes of this group, regardless of disease.

The literature, as well as some statements by women in this study, also provide support for the premise that, even when money is not an issue, there continue to be other barriers of importance to women’s receipt of care. One potential explanation, and another form of structural violence, is the low value placed on women and their roles in Bangladesh. Barriers to breast cancer care literature inconsistently defined “value of women,” so this study may contribute to a better understanding of this construct in relation to breast cancer care seeking among a rural, largely Islamic population in South Asia.

Only one person (a husband of a woman recommended for biopsy) *specifically* mentioned the role and value of women in society as a reason breast cancer services were not widely available. However, reports of study participants reinforced the idea that the role and value of women may be an independent influence on receipt of care for breast problems, and related to some of the barriers identified in this study.

One illustration of the low value of women the distribution of scarce resources. Although Bangladesh is a low-income country, there is evidence that women take a lower priority than men when scarce resources are required for health problems.

At the macro level, the lack of access to health facilities for treatment of breast cancer and low level of awareness of breast cancer and women's health issues, in general, suggests the low value of women. Individuals mentioned that important diagnostic services were not available for women at the government hospitals and that long-distance travel was required to receive needed care (to Dhaka or India). Furthermore, few female doctors were available (itself an indicator of women's opportunities in Bangladesh), and the majority of both men and women, even those receiving a biopsy, reported a low level of knowledge about breast cancer and its treatment, indicative of a low priority of this women's disease among other health problems in terms of health promotion activities. While one person indicated that knowledge of disease, in general, is low, other reports indicated that lack of knowledge about breast cancer is specifically a result of the low priority of women's health issues. A closer look at the relative importance of men's and women's diseases in Bangladesh may be warranted in order to provide a more precise statement about how the value of women plays out in national decision making about health priorities, and for breast cancer in particular.

This study perhaps more clearly illustrates the value of women as it relates to health decisions at the individual level. Some women, for example, mentioned that their husband or husband's family was not willing to give money to them to seek care. Most women, by nature of their gender roles as homemakers and because of their low levels of education, do not have their own resources to draw from. When the husband and

husband's family decides she cannot have access to family resources, the woman has few options—she may attempt to raise money from her community, or ask her parents or siblings to help if they are able. Women mentioned (as noted above) anger from family members about having to spend money on her problem, and neglect or divorce as a result. Some women also mentioned that their husband's issues took greater priority than their own, so they were unable to receive care.

The relatively frequent number of women who reported that their families did not care whether they lived or died, and did not concern themselves with her illness provided another example of the value of women within the marital family. Not only was this a form of passive emotional abuse in this study, but participants also described these sentiments as a reason for the lack of diagnosis and treatment for breast problems. This study could not determine precisely how these attitudes emerged, but the case study of a man and woman who married for love and in which the woman received the treatment she requested (despite it being ineffective homeopathic treatment), suggests that arranged marriages in which women are viewed primarily as fulfillers of specific duties (versus that of a source of love and emotional support) may fall apart when those duties are no longer able to be fulfilled. Further study of this dynamic is required for a better understanding of its influences on receipt of breast cancer care for women.

As suggested above, the findings of this study also help to understand why prior studies of women with breast problems in Bangladesh identified fear of or actual abuse in relation to a breast problem. While abuse might have a relationship with care seeking for breast problems (Table 21), it appears more likely to be a product of structural violence (including poverty and the value of women) rather than a unique barrier to care. Theory

on the causes of violence against women suggests that threats to gender identity may be one reason violence occurs (Felson & Tedeschi, 1993). This study strongly suggests that breast cancer threatens men's and women's gender identity, which is particularly important in the context of a male-dominated society with traditional gender roles. Women who are unable to perform their duties threaten the make-up of the family, including the role of the husband and father. Men who are unable to fulfill their role as a provider due to strains on resources also face identity threats. In societies where violence is an acceptable outlet for threats to identity, one could hypothesize that family instability introduced via a breast problem may cause additional violence (particularly when broadly defined, as it was for this study).

The overall "background" level of abuse reported by women in this study, along with literature on the topic, also suggests that abuse (both passive and active abuse) is an accepted part of many women's lives, and that breast problems on their own do not cause abuse. A curious finding noted in Chapter 6, however, introduces questions about whether women become more conservative and accepting of abuse from their husbands in times of serious illness. Future studies may consider measuring whether abuse escalates toward women when a breast problem or another serious health issue is identified, and whether, as suggested by violence theory, this threat to gender identity is a cause for increased violence; this study was unable to make that determination.

As noted in Chapter 4, violence against women, particularly violence within the family, is not a well-understood phenomenon in Bangladesh. Furthermore, loose legal enforcement of the Domestic Violence Act of 2010, and social and cultural interpretation of the law mean that existing laws do not sufficiently protect women. This particular

illustration of abuse, regardless of its limitations, may provide an important source of information about abuse within the household, as well as emphasize the vulnerability of women with potentially life-threatening disease, and the need for increased protection of women within their homes.

Implications for Strategies to Reduce Delay for Breast Problem Care Seeking

The vast discrepancy in survival for breast cancer between lower and higher income countries worldwide is itself a form of violence against women in lower- and middle-income countries (LMIC). As suggested by structuralist perspectives on violence toward women (K. L. Anderson, 2005) women's location in the world and within her own society via her gender, economic status, and potentially other factors not explored in this study (e.g., religious affiliation), impacts these outcomes and the quality of life she experiences throughout the decision to seek and receive care.

The results of this study in relation to this perspective suggest that improving outcomes for breast cancer requires both short- and long-term strategies, which may correlate with more individual-level barriers amenable to rapid change and longer-term efforts to address structural barriers, respectively.

Efforts to change the status of women are ongoing and cannot be expected to have immediate impacts, but are an extremely important part of improving the lives of women with breast problems; not only their survival but also the quality of life they live with disease; this also applies to poverty reduction and health system improvement efforts. Furthermore, addressing stigma needs to be part of larger efforts to improve access to affordable health services, increase the value of women in society, and improve the livelihoods of families. When husbands and in-laws know and believe that there is

affordable, accessible, effective care for breast cancer, they may feel less threatened and more likely to seek immediate treatment for breast problems (many of which will be non-cancerous). Concurrently, other family members may be more willing to provide important emotional, financial, and logistical support.

Coordinating breast cancer care with efforts to address other structural issues can produce a cumulative positive effect on numerous fronts. Coordinated efforts have the potential to reduce, overall, the level of abuse experienced by women in Bangladesh. Consequently, barriers of fear and fatalism, which have their roots in the poor outcomes experienced by women with breast problems in Bangladesh, will also subside.

Shorter-term strategies, however, are also needed to reduce delay in care seeking and improve outcomes. First, given the widespread use of alternative medicine, specifically homeopaths in Bangladesh, and reports of homeopaths helping women to engage in the allopathic health system, it makes sense to train and incentivize homeopaths to identify early signs of breast cancer and to create referral networks to diagnose women with these signs. Poverty, being one of the most often cited reasons for choosing homeopathy, as well as women's modesty and difficulty leaving the home or village confines, needs to be considered in this equation, and suggests that more local, female doctor services are needed. Few doctors are eager to work in remote villages, so efforts to incentivize doctors to visit villages with portable diagnostic tools such as an ultrasound, can help to identify and facilitate treatment for cases that warrant further investigation after a clinical breast exam. Breast cancer is still a relatively rare disease in Bangladesh and health systems are not equipped to deal with a flood of "worried well."

Well-coordinated and targeted diagnostic efforts, however, may result in efficient use of limited resources and ensure that the right women receive early diagnosis and treatment.

Additionally, there is evidence that lack of knowledge about breast cancer symptoms and effective treatment options interfered with the receipt of treatment for women, even when money and support were not barriers to care. This finding suggests that additional health promotion efforts can have a rapid impact on care seeking, resulting in the diagnosis and treatment of women with breast problems at an earlier stage.

Finally, ensuring that individuals who most need services and financial support actually receive those services can be an immediate task for government hospitals to address. While it may require longer-term efforts to change the culture of favoritism, systems to reduce discrimination and provide care to those most in need can positively affect breast cancer outcomes.

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APPENDIX A

BARRIERS TO CARE LITERATURE REVIEW METHODOLOGY

Articles included in this literature review were primary research studies conducted in South Asian countries and with South Asian immigrants (first generation or greater) living in other countries. A broad array of studies were included to capture as much information as possible about factors contributing to this review's primary question, namely, *what are barriers to breast cancer care for South Asian populations identified in the literature*. Both qualitative and quantitative descriptive and correlative research studies were included, with no restrictions on the number of subjects or study design. However, a negative relationship between a factor (a barrier, whether or not this is explicitly defined as such) and one of the three behaviors of interest (screening, diagnosis or treatment) must have been identified, whether through self-reports (case studies, focus groups, open-ended surveys or interviews) or statistical analyses of factors and behavioral outcomes. Articles relating a factor to breast cancer outcomes only (i.e., survival) were excluded from this analysis. Factors contributing to improved breast health behaviors were also not reviewed. Barriers to breast cancer self-exam (BSE) may be similar or different from those of receiving clinical breast exam (CBE, which refers to an exam conducted by a health provider), mammography, diagnosis, or treatment. For this reason, an effort was made to distinguish the results of articles that examine one or more of these behaviors where possible.

Published peer-reviewed journal articles, dissertations, and masters theses were included, ranging from year 2000 to 2015. Little published information was available prior to this time, or has been covered in prior reviews of a similar nature. The Arizona State University libraries were used to conduct this literature search, particularly the

EBSCOHost, ERIC, PubMed, ProQuest, PremierSearch, SagePremier, and ScienceDirect databases, and cross-referenced with Google Scholar findings. Search terms included: barriers to breast cancer care, barriers to breast cancer screening, barriers to breast cancer diagnosis, barriers to breast cancer treatment; as well as a search of these terms by each South Asian country included in this review.

APPENDIX B

BARRIERS TO BREAST CANCER CARE AMONG SOUTH ASIAN POPULATIONS LITERATURE REVIEW SUMMARY TABLE

[Consult Attached Files]

Windows MS Excel

APPENDIX C

INSTRUMENTS

[Consult Attached Files]

Windows Adobe Acrobat Reader

APPENDIX D

INFORMATION FORM

Arizona State University (ASU) Study on Breast Problems in Bangladesh

INFORMATION LETTER

Date_____

Dear _____:

I am working for a graduate student in the Global Health Program at Arizona State University in the USA named Heather Story Steiness, who is working under the direction of Dr. Daniel Hruschka, also of Arizona State University. I am conducting a research study to better understand the things that prevent or make it easier for women to receive treatment for breast problems in Bangladesh. This research may improve services for women like you. I am inviting your participation, which will involve an interview lasting about forty-five minutes at a location that we agree upon. You will sit with the interviewer and she (for women) or he (for men) will record your answers on an electronic tablet/computer, which will also include audio recording some of your answers. Your answers will be kept private. We will ask you questions about your current living conditions, experience of violence in your family, and questions about your experience with and feelings about serious breast problems. You have the right not to answer any question, and to stop the interview at any time. We would like to interview you again in three months for a similar interview.

Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time, there will be no penalty. If you currently or in the future decide to use health services from Amader Gram or any other health provider, your participation or decision not to participate in this study will not affect your treatment in any way.

You must be 18 or older to participate in the study.

Some of the interview questions could make you uncomfortable or bring up concerns about your health or other issues. At any point during the interview if you feel uncomfortable, we ask that you tell the interviewer and we will do our best to address your concerns. You always have the right to stop the interview if you do not wish to continue.

Although there are no direct benefits to you for participating in this research, your thoughts and experiences will help us understand how to better treat women in Bangladesh and other parts of the world with breast problems.

All information obtained in this study is strictly confidential. We will conduct the interview in a place where you feel comfortable answering questions about

your health. The results of this research study may be used in reports, presentations, and publications, but the researchers will not identify you. In order to maintain confidentiality of your records, Mrs. Story Steiness and the research staffs will identify your interview only with a number. A record linking your name with the number will be kept on a secure computer to which only research staffs have access.

I would like to audiotape this interview. The interview will not be recorded without your permission. Please let me know if you do not want the interview to be taped; you also can change your mind after the interview starts, just let me know. Audio recordings will be destroyed after the words are written on paper (transcribed), and all written documents will be kept on a secure, password protected computer that only research staffs can access.

If you have any questions concerning the research study, please contact the research team at: _____ (Interviewer) or Tahmina Ferdousy (Research Coordinator) at _____. If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788. Please let me know if you wish to be part of the study.

Would you like to have a copy of this information? (If yes, provide a written copy of this document; If no, provide a contact information sheet so the potential participant knows how to contact you with questions or report concerns to the ASU Office of Research Integrity and Assurance).

AMADER GRAM CONTACT INFORMATION

Interviewer/Phone Number: _____

Research Coordinator: Tahmina Ferdousy:

Arizona State University Office of Research Integrity and Assurance:
Chair, Human Subjects Institutional Review Board in the: (US) 480-965-
6788.

APPENDIX E

ARIZONA STATE UNIVERSITY (ASU) OFFICE OF RESEARCH INTEGRITY AND ASSURANCE STUDY APPROVAL

[Consult Attached Files]

Windows Adobe Acrobat Reader

APPENDIX F

ASU PARTICIPANT CONTACT INFORMATION FORM

We want to ensure your privacy, but it is also important that we be able to contact you if we have questions about your interview and to follow-up with you in three months. Please help us by providing information about where you live, and telling us the best way to contact you.

Name of Participant:_____

Age:_____

Division:_____

District:_____

Upazila:_____

Union/Ward:_____

Village/Mohalla/Block:_____

Phone Number (also indicate who carries the phone):_____

If we are unable to reach you directly, who are some people we could call to locate you (we will not discuss the study or your participation)?:

Name	Relationship	Phone Number
_____	_____	_____
_____	_____	_____

What is the best way to reach you?

Anything else we should know about getting in touch with you?

APPENDIX G

SUPPLEMENTAL TABLES

Table 26: Women's Age, Husband's Age, Marital Status, and Religion; Breakdown by Female Study Groups and 2007 Khulna Division Ever Married Women Aged 15-49

	Women Recommended for Biopsy n=19	Women Not Seeking Care n=24	2007 Khulna DHS (Ever married women aged 15-49 years) n=1711
Age: Mean (Range)	37.7 (23,60)	32.2 (18,63)*	30.9 (15,49)*
Husband's Age: Mean (Range)	50.3 (30,80)	42.5 (21,90)*	39.6 (17,91)
Marital Status: n (%)			
Currently Married	15 (75.0)	20 (80.0)	1564 (91.4)
Separated	2 (10.0)	2 (8.0)	26 (1.5)
Deserted	0	0	20 (1.2)
Divorced	0	1 (4.0)	34 (2.0)
Widowed	2 (10.0)	1 (4.0)	67 (3.9)
Never Married	1 (5.0)	1 (4.0)	0
Religion: n (%)			
Islam	18 (90.0)	25 (100.0)	1565 (91.5)
Hinduism	2 (10.0)	0	146 (8.5)
Buddhist	0	0	0
Christian	0	0	0
Other	0	0	0
School or Madrasa: n (%)			
School	16 (80.0)	17 (68.0)	1207 (70.5)
Madrasa	0	1 (4.0)	19 (1.1)
Both	0	0	3 (.2)
None	4 (20.0)	7 (28.0)	482 (28.2)
Highest level of school: n (%)			
None			
Primary (1-5)	4 (20.0)	7 (28.0)	482 (28.2)
Secondary (6-10)	4 (20.0)	4 (16.0)	495 (28.9)
College +	7 (35.0)	12 (48.0)	575 (33.6)
	5 (25.0)	2 (8.0)	159 (9.3)
Husband's education level: n (%)*			
None	6 (35.0)	0	546 (31.9)
Primary (1-5)	0	8 (32.0)	446 (26.1)
Secondary (6-10)	4 (20.0)	6 (24.0)	434 (25.4)
College+	9 (45.0)	5 (20.0)	284 (16.6)

Table 27: Household Wealth Indicators by Study Group and 2007 Khulna Division Households

	Women Recommended for Biopsy n=20	Women not Seeking Care n=24	Husbands of Women Recommended for Biopsy n=21	2007 Khulna Division Households n=2223
Sum of Wealth Indicators (Max 16): Mean (Range)	6.1 (2,10)	4.8 (2,10)	7.6 (3,12)	4.8 (0,12)*
Average monthly household income: Mean (Range)	8300 (2000,20000)	5560 (2000,15000)	12150 (2000, 30000)	NA
“Compared to Neighbors”: n (%)				
Better than neighbors	6 (30.0)	2 (8.0)	8 (38.1)	NA
Same as neighbors	5 (25.0)	8 (32.0)	10 (47.6)	
Worse than neighbors	9 (45.0)	15 (60.0)	3 (14.3)	

Table 28: Women's Empowerment Indicators by Female Study Groups and 2007 Khulna Division Women Aged 15-49

	Women Recommended for Biopsy n=20	Women not Seeking Care n=24	2007 Khulna DHS (Married Women aged 15-49 years) n=1711
Work Outside the Home for Pay in Past 12 Months: n (%)			
Yes			
No	4 (20.0) 16 (80.0)	5 (20.0) 19 (80.0)	682 (39.9) 1029 (60.1)
Decision Making for Daily purchases: n (%)			
Respondent	6 (30.0)	3 (12.0)	556 (32.5)
Husband	10 (50.0)	16 (64.0)	305 (17.8)
Respondent and Husband			515 (30.1)
Someone Else		2 (8.0)	176 (10.3)
Respondent and Someone Else	3 (15.0)	3 (12.0)	159 (9.3)
Decision making for health care for self: n (%)			
Respondent	3 (15.0)	9 (36.0)	267 (15.6)
Husband	12 (60.0)	10 (40.0)	462 (27.0)
Respondent and Husband	2 (10.0)	2 (8.0)	738 (43.1)
Someone Else	2 (10.0)		116 (6.8)
Respondent and Someone Else	1 (5.0)	3 (12.0)	128 (7.5)
Goes for health care independently or with small children: n (%)*			
Yes	8 (40.0)	14 (56.0)	1153 (67.4)
No	11 (55.0)	7 (28.0)	558 (32.6)
Attitude toward violence (Scale of 0 to 4 where higher is more accepting): Mean (Range)	2.5 (0,4)*	3.1 (0,4)*	0.6 (0,4)*

*1 goes for health care independently or with small children missing for women seeking care, 4 missing for women not seeking care; 2 attitude toward violence missing for women recommended for biopsy, 4 missing for women not seeking care, and 12 missing for 2007 Khulna DHS.

Table 29: Barriers by Study Group

	Women Recommen ded for Biopsy	Women Not Seeking Care	Husbands of Women Recommen ded for Biopsy	OVERALL	Rank
Barrier Reported: n (%)	n=19	n=24	n=20	n=63	
Health System Barriers					
Access	8 (42.1)	11 (45.8)	11 (55.0)	30 (47.6)	3
Health System Interaction	11 (57.9)	4 (16.7)	8 (40.0)	23 (36.5)	5
Economic Barriers					
Inability to Pay	13 (68.4)	16 (66.7)	15 (75.0)	44 (69.8)	2
Economic Control	1 (5.3)	4 (16.7)	0	5 (7.9)	10
Attitude, Belief and Norm Barriers					
Fatalism	3 (15.8)	4 (16.7)	10 (50.0)	17 (27.0)	6
Fear of Treatment	13 (68.4)	14 (58.3)	2 (10.0)	29 (46.0)	4
Modesty	3 (15.8)	7 (29.2)	6 (30.0)	16 (25.4)	7
Religion	0	0	0	0	12
Stigma	2 (10 .5)	3 (12.5)	6 (30.0)	11 (17.5)	8
Women's Travel Outside the Home	0	3 (12.5)	0	3 (4.8)	11
Knowledge Barriers					
Exclusion from Knowledge	1 (5.3)	0	2 (10.0)	3 (4.8)	11
Lack of Knowledge	12 (63.2)	21 (87.5)	17 (85.0)	50 (79.4)	1
Other Disease	4 (21.1)	3 (12.5)	0	7 (11.1)	9
Other Barrier	2 (10.5)	3 (12.5)	2 (10.0)	7 (11.1)	9
Unique Barriers Reported: Mean (Range)	4.1 (1,8)	4.3 (1,9)	4.0 (0,7)	4.14 (0,9)	

APPENDIX H

CODE BOOK

[Consult Attached Files]

Windows MS Excel

BIOGRAPHICAL SKETCH

Heather Story Steiness has worked in the field of public health both domestically and abroad for over two decades. She received her Master of Public Health from the University of Michigan. She started her work in Bangladesh in 2000, first with a US Agency for International Development fellowship to provide technical assistance for rural health clinic development, and later with the International Breast Cancer Research Foundation to manage breast cancer clinical trials based in the US, Asia, and Africa. In Bangladesh, she helped to develop and implement a comprehensive breast care program that served women in the Khulna Division. Her research interests include women's health issues among underserved and lower-income populations domestically and abroad and the role of structural violence in preventing optimal health.